Understanding the Support Needs of Parents with Inflammatory Bowel Disease and their Children

Volume I of II

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Abstract

Although there is growing interest in the support needs of disabled parents, little is known about the experiences and needs of families when a parent has a chronic illness. This thesis represents the first investigation into the support needs of parents with inflammatory bowel disease (IBD) and their children. IBD is a chronic illness that can cause a range of debilitating symptoms, including some which are associated with considerable social stigma.

The theoretical frameworks underpinning the research are the transactional model of stress and coping, the family-systems illness model, and the resource-based approach to intervention. The research began with a qualitative phase, in which two exploratory studies were carried out, one involving parents with IBD, the other their children aged 6-20 years. Findings from this research led to a quantitative phase, which included a postal survey of 178 parents with IBD and 74 of their children, aged 11-16 years.

The research found that parents' greatest difficulties in relation to parenting were with household chores, providing for financial needs, and social activities. In addition, rates of anxiety and depression amongst parents were significantly higher than reported in a UK community sample. Through regression analysis it was possible to account for 65% of the variance in depression. Significant predictors of depression were perceived IBD-related health status, parenting difficulty, and an interaction between family support and parenting difficulty. Anxiety was not well explained by regression analysis. Parents reported that their greatest need was for psychological support, including stress-management and counselling.

Despite the difficulties parents experienced, their children, at least in the adolescent years, appeared to be largely unaffected in terms of their social life with peers, domestic responsibilities, school attendance, and relationships with parents. However, they did experience significantly more emotional and behavioural difficulties than expected for their age range. Preliminary research suggests these difficulties are associated with the child's age, whether the child has an illness or disability, parenting difficulties, and the child's relationship with their parents. A substantial proportion of parents and young people reported a need for age-appropriate information for children on IBD and its treatment.

It is concluded that families can best be supported by interventions targeted at the parent, though information for children on the condition and its treatment would also be valued.

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Author's declaration

Study 1 of this thesis – the qualitative research with parents, was funded by the National Association of Colitis and Crohn's Disease (NACC). This study was designed and carried out jointly by the author and Professor Patricia Sloper while employed at the Social Policy Research Unit (SPRU), University of York (see Chapter 5 for further details). A report on this research was written for NACC by the author in 2000.

The remaining three studies were designed and carried out solely by the author. This work was funded by a PhD studentship, awarded by the Department of Health Sciences, University of York. In order to increase the reliability of the data analysis for Study 2 – the qualitative research with children, Lynne Kendall, a researcher in the Department of Health Sciences, acted as a second data coder. Her role is described in further detail in Chapter 7.

The views expressed in this thesis are those of the author and not necessarily those of the funders.

Efforts have been made to disseminate the findings from this research as they have arisen. A list of publications and presentations by the author follow below.

Publications

Mukherjee,S. Sloper, P. and Lewin, R. (2002) The meaning of parental illness to children: The case of inflammatory bowel disease, *Child: Care, Health and Development,* 28 (6) : 479-485.

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Conference/Seminar presentations

'The experience of parental chronic illness: The case of inflammatory bowel disease', School of Nursing Studies, University of Northumbria, December 2002.

'Understanding the impact of inflammatory bowel disease on parents and their children', NACC Support Group Meeting, Norwich, September, 2002.

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'When Mum or dad feels ill: A research update'. NACC-in-Contact Workshop, London, May 2002.

'Understanding the impact of inflammatory bowel disease on parents and their children'. NACC-in-Contact Workshop, London, May 2001.

'Parents with inflammatory bowel disease: The hidden stress'. The British Psychological Society Centenary Annual Conference, March 2001, Glasgow.

Part I

Introduction

CHAPTER 1

Introduction to the Thesis

Opinions on the impact of chronic illness and disability on parents and their children have been expressed by a wide range of people, including nurses, counsellors, family therapists, disabled parents, supporters of the carers' movement, disability rights activists, and academics within sociology and psychology. A taster of the diversity of opinion on the subject is provided by the following quotes:

> *Disabled parents have strong sense of themselves as regular parents dealing as others do with the ups and downs of family life.*
> (Wates, 1997: 6)

> *Pain, physical incapacity, fatigue, absence, and anxiety had altered what they (parents) could give and receive, leaving them with an altered sense of having prematurely robbed their sons and daughters of their childhood.*
> (Altschuler and Dale, 1999: 23)

> *Parental ill health or disability will always be a determinant in children undertaking care-giving roles in the family.*
> (Aldridge and Becker, 1999: 312)

> *These children have a high degree of sensitivity to others, particularly disabled persons...they conceptualise a greater number of friendship expectation dimensions, demonstrating a potential for mature friendship relations with peers.*
> (Blackford, 1988: 34)

In the midst of this disparate literature, it is sometimes difficult to obtain a clear view of what daily life is like for families in which a parent is ill or disabled, whether they need support from outside agencies, and if so, what form this should take. It is even more difficult to answer these questions in relation to inflammatory bowel disease (IBD) since there has been no research in this area. This thesis represents the first investigation into the support needs of parents with IBD and their children.

1.1 An Introduction To IBD

A little knowledge about IBD and its treatment makes it apparent why this condition *might* have implications for parents and their children. Inflammatory bowel disease (IBD) is a chronic illness for which there is no known cure (Thompson, 1993), although effective treatments are available. There are two main forms of IBD, ulcerative colitis (UC) and Crohn's disease (CD). The two conditions cause similar problems for the patient. Symptoms include diarrhoea, with blood and mucus, abdominal pain, weight loss, and sometimes vomiting. Fatigue is often prominent and perceived as disabling. Complications include anaemia, malnutrition, intestinal obstructions, abscess formation, and fistulas. There are also a number of associated diseases which affect other organs, most frequently the joints, skin, liver, eyes and kidneys, and which may be of as much significance to the patient as the IBD itself (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 inpatient.

Although CD and UC are usually studied together, they are two distinct medical conditions and have a different clinical presentation, complications, morbidity, and psychological impact (Drossman, 1996). UC is confined to the colon, whereas CD can affect any part of the digestive system. In CD inflammation also penetrates all layers of the gut, with chronic inflammation greatest in the sub mucosa, whereas in UC inflammation is confined to the mucosa of the colon. In the long term, patients with UC 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). 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 can be curative, but may mean the patient having an ileostomy or ileoanal 'pouch'. Surgery may also be effective in patients with CD, where it largely alleviates symptoms for a period of time, but the condition is likely to recur in other sections of the digestive tract (Worley, 1999; Thompson, 1993).

Within everyday life it has been suggested that people with IBD maintain a low profile. While some people may appear 'ill' because they are thin, pale and emaciated, or alternatively, because of the bloating effects of steroid treatment, many may not appear different. Furthermore, in a qualitative study of patients with ulcerative colitis, it was found

that, because of the embarrassing nature of some of their symptoms, many people attempted to conceal the nature of the illness to all but a few intimate friends or relatives (Kelly, 1992). Kelly comments:

> *With people who are not privy to the 'true' health status of the person, and hence where a normal identity is possible, then efforts of self are directed towards observing normality in interaction. The secrecy of the illness and the maintenance of that secrecy means that strangers and people who do not know are not involved in legitimating anything other than the apparently normal version of self. However, this is usually difficult to achieve alone and a group of 'cognoscenti' are drawn into the management of the illness in order that a successful, or at least an integrated life beyond the immediate family, can be achieved.*
> (Kelly, 1992: 52-53)

1.2 Aims And Objectives Of The Thesis

The overall aim of this thesis is to establish what support, if any, is needed by families in which a parent has IBD. There are three main research objectives:

- To determine the impact of IBD (both positive and negative) on:
  - parents in their parenting role;
  - the adjustment of their children;
- To identify factors which moderate and mediate this impact;
- To gather parents' and children's views on the support that would be helpful to families.

Critiques of research on parental illness have noted that it has tended to be negatively biased, focussing on parenting difficulties, and children's emotional and behavioural problems, and role as young carers (Blackford, 1999; Kahle and Jones, 1999; Korneluk and Lee, 1998; Wates, 1997). In this study, efforts will be made not to assume parental illness is problematic and to measure a wide range of outcomes for parents and children.

An important element of this thesis is that it investigates both mediating and moderating variables. The significance of mediators is that they explain why a particular phenomenon has a particular effect on an individual. In other words, in the context of this study, the search for mediating mechanisms is an attempt to answer the question 'What is it about parental IBD that has an impact on parents and their children?'. It is only through

uncovering mediating mechanisms that we can devise effective interventions for families (Rutter, 2000). Moderators *'affect the relationship between two variables so that the nature of the predictor on the criterion varies according to the level or value of the moderator'* (Holmbeck, 1997: 599). An investigation into moderators answers the question 'What factors influence the level of effect experienced by parents with IBD and their children?'. In the context of this thesis, this is useful because it identifies individuals most likely to need support.

1.3 Why The Research Is Worthwhile

There are a number of reasons why this research is worthwhile. First, this research will fill a gap in research knowledge. In general, studies investigating the impact of parental illness and disability are sparse. Research on the experiences of parents with an illness or disability is limited to a small number of exploratory studies. Research into the impact of parental illness on children has examined a narrow range of conditions, and in many studies there are flaws in the research design and methods. As already stated, no study has ever been carried out to investigate the impact of IBD on parents and their children, or to identify their support needs.

Secondly, due to demographic, medical and life-style trends, the number of parents with a chronic illness is likely to rise in the years ahead (Kahle and Jones, 1999). A trend towards minimising hospital stays, and expecting family members to provide care at home, is also likely to increase the amount of time children spend with a parent who is unwell. In other words, the proportion of the population affected by parental illness is likely to increase.

In relation to IBD specifically, hospital-based records suggest between 150-200 per 100,000 have the condition at any one time (Andres and Friedman, 1999; Thompson, 1993), so it is not common. However, there is evidence to suggest that the number of people affected by CD is rising, with between a three and six fold increase in incidence reported across research sites between 1960 and 1987 (Andres and Friedman, 1999). In the UK, monitoring of CD in the 0-19 year old age group revealed a 50 per cent increase in incidence between 1981 and 1992 (Armitage *et al.*, 1999). It is also worth noting that onset of IBD occurs most commonly between the ages of 15 and 40 years, peaking in late adolescence and early adulthood, so many people with the condition will either be parents or considering parenthood.

Thirdly, parents themselves support research in this field. A number of studies indicate that parents are concerned about how their illness interferes with their parenting ability (Kahle and Jones, 1999). Although there has been no previous research on the impact of IBD on parents and their children, a survey carried out in 1995 of a random sample of 2400 members of the National Association for Colitis and Crohn's Diseases (NACC) in the UK suggests that it is an issue of concern to parents with IBD (Walters, 2000). Forty-two 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. Within the last few years, researchers concerned with disability rights have also drawn attention to the value of research in this area. They have suggested that, while care needs to be taken not to treat disabled parents as abnormal, or to undermine their self-worth, it is important to make their experiences visible and draw attention to any barriers or difficulties faced by parents (Wates, 1997; Morris, 1996). Only by doing this is it possible to secure appropriate support for parents.

1.4 An Overview Of The Methodology

In this thesis, a multi-method approach is adopted to address the research objectives, with data collected using qualitative and quantitative techniques. Data were also collected from two separate sources – parents and children. As a result, there are four separate studies within the investigation (see Table 1).

Table 1: Overview of research

Phase One: qualitative research • Study 1: qualitative research with parents • Study 2: qualitative research with children
Phase Two: quantitative research • Study 3: survey of parents • Study 4: survey of young people

The specific reasons for adopting both qualitative and quantitative techniques, and collecting data from both parents and their children, are described in further detail below. However, before doing so, it is worth pointing out that the data sets are viewed as complementary, adopting the approach proposed by Mays and Pope (2000) in which findings from the different studies are used to ensure a more 'complete' picture of the phenomenon under investigation. As Bryman (1992) has pointed out, different methods

have different aims and therefore rarely tap into the same thing, even if they apparently examine similar issues.

1.4.1 The value of gathering qualitative and quantitative data

Since there has been no previous research in this field, it was decided the investigation should begin with a qualitative phase to develop an insight into the impact of IBD on parents and their children. The first study, which involved parents with IBD, was funded by NACC and data collection was carried out in the summer of 2000. Data collection for Study 2, involving children whose parents took part in study 1, began nine months later, during the spring of 2001. Findings from the qualitative research with parents informed the research with children.

The decision to carry out phase two of the research – the survey of parents with IBD and their children, was based on the need to quantify the experiences described in the qualitative research. Prospective audiences for this research, including families, service providers, and policy makers, may be interested in knowing what life is like for families in which a parent has IBD. However, they are also likely to want information on the scale of the issues being reported. Without such data it will be impossible to answer questions such as 'What proportion of parents with IBD are likely to need support?' and 'To what extent are children likely to benefit or experience difficulties as a result of a parent having IBD?' These are the types of questions which the second phase of the research aimed to answer. Secondly, the qualitative research suggested factors which appeared to moderate and mediate the impact of IBD on parents and children's psychological well-being. In order to test such hypotheses, it was necessary to have quantitative data. Data collection for the second phase of the research began in June 2002, and continued until March 2003.

1.4.2 Multiple data sources: The value of data from parents and children

In the past, research on parental illness has focussed primarily on outcomes for children. In this investigation, data were also collected on outcomes for parents. There were a number of reasons for doing so. First, in this thesis, the needs of parents as individuals were considered important in their own right. Secondly, as Drotar (1994) has pointed out, identifying and understanding the effects of health problems on parents is necessary if we are to avoid simplistic blaming of parents for any difficulties experienced by their children.

In relation to children's experiences and support needs, data were collected from both parents and young people. Data from parents are useful since it is their perception that it is most likely to determine whether help from outside agencies is sought for the child. However, if we are to obtain an accurate assessment of the impact of parental illness on children, it is also important to gather the views of children themselves. Evidence from a wide range of studies indicates that adults do not always have an insight into children's perspectives. When parents and professionals are asked what they think children think, feel or need, there are discrepancies between their reports and children's self-report (Hart, 1998; Beresford, 1997; Rosenbaum and Saigal, 1996). In relation to research pertinent to this thesis, there is evidence that the impact of parental illness on children's adjustment varies considerably depending on whether outcome measures are based on the child's self-report or reports by adults, such as parents or clinicians (Korneluk and Lee, 1998). In addition, from a children's rights perspective, the importance of enabling children to express their views through research is now widely accepted (Alderson, 2000; 1995; Boyden and Ennew, 1997; Beresford, 1995). Finally, within the public sector, it is recognised that children are consumers in their own right, and unless their perceptions are known services cannot respond to their needs (Hart, 1998; McGuire, 1998).

1.5 Theoretical Frameworks Underpinning The Research

> *No research is theory free. We can only look at things in certain ways because we have adopted, either tacitly or explicitly, certain ways of seeing.* (Silverman, 2001: 70)

The approach taken in this thesis is to begin by making no assumptions about the impact of IBD on parents and their children, developing hypotheses based on qualitative data collected from parents and children. However, it is widely accepted that even if researchers lack a clear set of hypotheses at the start of their research, they cannot help but be influenced by their prior knowledge of the literature, lay knowledge, including political values, previous research, and common sense experience (Silverman, 2001; Denzin and Lincoln, 2000; Brannen, 1992).

In this thesis, the decision as to which framework to adopt has been guided by the overall aims and objectives of the study. This means that first, and foremost, the theoretical approach should assist with identifying the support and resources useful to families in which a parent has IBD. Secondly, this study is specific to IBD and it was important to

adopt theories that aid understanding of the particular experiences of this group of patients. Thirdly, research on the effects of parental chronic illnesses upon children, 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. Finally, the theories chosen should be able to guide an investigation concerned both with the impact of IBD on parents *and* on their children.

Three frameworks have been drawn upon to deal with these aspects of the research. The theoretical framework underpinning the research is the transactional model of stress and coping (Lazarus, 1999; Lazarus and Folkman, 1984). This has been supplemented by the family-systems illness model (Rolland, 1999; 1984), and the resource-based approach to intervention (Dunst *et al.* 1988). A detailed description and critique of these theories, as well as the implications of adopting them, is provided in Chapter 3. However, it is important to acknowledge at this point that, by adopting a stress and coping framework as the primary theoretical framework, the study focuses on outcomes for individuals. Increasingly services for families are concerned with taking a holistic approach to support, acknowledging that in order to assist families you need to look at the needs of every family member. It is sometimes argued that a family systems theory, which focuses less on the parent-child relationship, and more on families as a whole, is useful in that it leads to interventions which are non-blaming and focus on family strengths (Halpern, 2000). From a family systems perspective the unit of analysis should be the family. However, descriptions of families as a social system do not necessarily characterise the state of mind of individuals within them (Lazarus, 1999). While in agreement with sentiments expressed by Patterson and Garwick (1994: 139) that '*the primary goal for work with families who are managing chronic illness should be to promote the healthy functioning for all family members*', in order to be able to do this it is necessary to be aware of the concerns and needs of individual family members.

1.6 A Reflexive Position

Within the qualitative research paradigm, 'reflexivity' is considered an important part of providing a clear account of the process and increasing the credibility of the research. 'Reflexivity' refers to sensitivity to the way in which the researcher and research process have shaped the data (Mays and Pope, 2000). Through personal accounting, the researcher becomes aware of how their own position (gender, race, class, and power

within the research situation) and interests shape all stages of the research process, including the questions that are asked and ignored, who is studied, and how data are analysed (Hertz, 1997). Furthermore, the researcher's attributes are acknowledged to shape the relationship formed with respondents and hence the information that can be obtained (Reinharz, 1997).

In this chapter, attention has already been drawn to the diverse range of people who have informed the debate on parental illness and disability. In the literature review the way in which these positions have influenced the research evidence will be examined in greater depth. It is therefore seems only fair that I should be clear about my own background, and how this has influenced this thesis.

For most of working life I have been employed in research. Academically, my training includes a degree in psychology, followed by a Masters course in child development. Both courses favoured a quantitative research paradigm. However, subsequent employment within a research department where qualitative methods were valued has given me an insight into the potential benefits of combining both approaches within one study. Having worked largely within university departments, I have no allegiance to any group of practitioners or service provider. As the outset of the research, I was not a parent, nor did I have any close family or friends who were experiencing an illness or disability whilst bringing up a family. In addition, I had no knowledge of inflammatory bowel disease. Quite clearly I was an outsider to the world of parents with IBD and their children, which has both advantages and disadvantages. As Bolak (1997: 97) explains:

> *While a foreign researcher runs the risk of being culture blind, an indigenous researcher runs the risk of being blinded by the familiar.*

Whilst being an 'outsider' meant that I had no vested *personal* interest in the findings, as a researcher there is sometimes a sense of needing to produce 'findings'. In the context of this study, this could lead to a search for problems in the lives of parents with IBD or their children, something for which previous research in the field of parental illness has been heavily criticised. To help avoid this tendency to search for problems, my position at the outset of this research was that, whatever the findings of this thesis, the research could potentially be helpful in preparing patients for, and supporting them through, parenthood. If there are positive consequences for parents and 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. Evidence of any difficulties, along with data on the type of support wanted by parents and children, will also inform practitioners about the services needed by families in which a parent has IBD.

1.7 Structure Of The Report

The remaining chapters that make up this thesis fall into four parts. **Part II (*Chapters 2-4) provides the background to the research,*** covering literature published up to and including 2002, when the final stage of the research was undertaken. *Chapter 2* provides information on IBD, focussing on what having the condition means for patients today, and the potential implications for parents. *Chapter 3* outlines the theoretical frameworks adopted, and the how this has influenced the research undertaken. In *Chapter 4*, the empirical research on the impact of illness on parents and their children is reviewed.

Next, in ***Part III (Chapters 5-8) phase one of the research is described*** - the qualitative research with parents and their children. *Chapter 5* describes the design and methods of Study 1 - the qualitative research with parents. *Chapter 6* reports on the findings, providing an insight into the experiences of parents who have IBD. Since this research informed the design of Study 2 – the qualitative research with children, as well as the quantitative phase of the research, a summary of the findings is given at the end of the chapter. *Chapter 7* goes on to describe the research design and methods of Study 2 and *Chapter 8* reports on the results. Once again, since the results of this study influenced the design of the next phase of the research, a summary of the findings is provided at the end of the chapter.

Part IV (Chapters 9-12) deals with the second phase of the research - the quantitative survey of parents and their children. *Chapter 9* describes the survey research design and methods. In the following two chapters, the descriptive analysis of the survey data is reported. *Chapter 10* deals with the data on parents and C*hapter 11* with the data on children. In C*hapter 12* conceptual models describing factors that influence the psychological distress experienced by parents with IBD and their children are tested.

Finally, ***in Part V (Chapter 13), the research and its findings are discussed.*** This includes the strengths and limitations of the various elements of the research, a summary of the findings and how they fit with previous studies, reflections on the theoretical

frameworks adopted, recommendations for service providers, and reflections on how the investigator's outlook on the research has changed during the course of the work. Finally, conclusions are drawn about the support that should be offered to parents with IBD and their children.

Part II

Background

CHAPTER 2

Understanding IBD

2.1 Introduction

IBD was first recognised as a disease just over 100 years ago (Kirsner, 1988). Since this time, considerable progress has been made in the diagnosis and treatment of the disease, resulting in marked improvements in the prognosis for patients. The purpose of this chapter is to describe what the condition means for patients today. It covers the etiology of IBD, the relationship between stress and disease activity, the investigative and treatment procedures patients undergo, fertility and pregnancy, the impact of the condition on quality of life, and psychological well-being. The chapter ends by reflecting on the implications for parents with the condition. A glossary of terms used in this chapter is provided on page 267-268.

2.2 The Etiology Of IBD

Many different factors have been implicated in the etiology of IBD. Initially microbial infection was considered the primary cause of the disease. In the 1920s milk allergy was implicated, and the study of immune response became one of the most active areas of etiological research. In 1930s, psychogenic and psychoanalytical theories became popular and exerted an influence on treatment until the 1960s (Kirsner, 1988; Aronowitz and Spiro, 1988). An additional reasons for people perceiving IBD as psychosomatic is that it is often confused with irritable bowel syndrome, a common condition in which there is recurrent abdominal pain with constipation and/or diarrhoea, but where there is no general deterioration in health and where inflammation is absent (Kirsner, 1988). By the 1960s gastroenterologists were less convinced of the role of emotions in the disease. This was due to the many flaws in studies aimed at showing that onset of symptoms was preceded by psychiatric difficulties or emotional upset, and the failure of psychotherapy to provide a cure for the condition at the very time when rapid improvements were being made in medical treatment as a result of developments in abdominal surgery and the successful introduction of steroid therapy (Kirsner, 1988; Aronowitz and Spiro, 1988). Unfortunately, it has been suggested patients with IBD continue to suffer due to the condition being perceived as psychosomatic (Levenstein, 2002; North *et al.*, 1990).

Today the etiology of IBD remains unknown, but it is thought the condition is the result of an abnormal immune response to an environmental trigger in people who are genetically susceptible to the condition (Worley, 1999). The presence of a family member with IBD is the strongest single risk factor of developing the condition, though the level of risk is low (Ahmad *et al.,* 2001; Andres and Friedman, 1999). For example, in a study of patients with CD attending outpatient gastroenterology clinics, the age–adjusted risk of having IBD was 4.8 per cent for first-degree relatives (siblings, parents and offspring), with the highest level of risk found in offspring (10.4%) (Peeters *et al.,* 1996).

2.3 The Relationship Between Stress And Disease Activity

Although stress is no longer considered the *cause* of IBD, its role in the exacerbation of disease activity continues to be debated and investigated today. One of the main reasons for the interest 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 (Drossman, 1988; Theis and Boyko, 1994).

When reviewing the research investigating the relationship between stress and disease activity, at first glance it can appear as if there is no consistent pattern of findings across studies. However, the research is complicated by the fact that investigators have assessed stress using different measures – measures of stressful life events and daily hassles. The measurement of life events is based on the assumption that major life events, whether positive or negative, are stressful and lead to a change in health (Lyon, 2000). Daily hassles are concerned with minor daily experiences appraised as salient to the individual, and their measurement is more in keeping with the transactional theory of stress and coping (Lazarus, 1999). Here it is suggested that nothing can be assessed as stressful unless it has been appraised as such by the individual (see Chapter 3 for further details). When these measurement differences are taken into account, it becomes apparent that, while there is little support for a strong relationship between adverse life events and IBD, there is a trend for daily hassles to impact on symptoms (for a review of the literature see Searle and Bennett, 2001). Other evidence supporting a link between stress and disease activity 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). Whilst most studies aim to investigate the impact of stress on disease activity, it is also possible that having IBD makes everyday life events more stressful for individuals. In two studies IBD patients reported fewer stressful life events, but more perceived stress, than control groups (Sewitch *et al.*, 2001; von Weitersham *et al.*, 1992). It would seem that although patients with IBD do not experience more stressful events than those without the condition, they tend to feel more overwhelmed by such events. This is perhaps not surprising given that coping with stressful events is likely to be more taxing when experiencing symptoms of IBD.

2.4 Investigative Procedures And Medical Treatment

Patients with IBD undergo a number of tests, first to reach a diagnosis, and then to monitor progress. Treatment for both UC and CD includes drug therapy, to reduce symptoms, inflammation, and suppress the immune response; dietary therapy; and surgery. These investigations and treatments have resulted in significant improvements in the prognosis for people with IBD, but many are unpleasant and have unwelcome side-effects.

2.4.1 Investigative procedures

Examinations of the digestive system, for the purposes of diagnosis, making decisions about management of the condition, and cancer surveillance, are aided by endoscopy. Here a fiberoptic instrument is inserted into the body and used to display an image of the digestive system on to a monitor. There are various forms of endoscopy, each using a different instrument to examine a particular section of the digestive tract. Some procedures, although uncomfortable, are relatively painless (rigid sigmoidoscopy and esophagogastrodudenoscopy). In the case of esophagogastrodudenoscopy, Valium is given to relax the patient. Other procedures (fibersigmoidoscopy and colonoscopy) cause pain, and fibersigmoidoscopy may cause the patient to defecate or pass gas. As a result, patients are sedated before a colonscopy, and an enema is usually given prior to fibersigmoidoscopy (Thompson, 1993). In addition, colonoscopy requires seven days of preparation, including the withdrawal of various medications and alterations to diet.

Other techniques used to investigate the disease include X-rays, barium enema, ultrasound, and computerised tomography (CT Scans). *X- rays* can be used to detect abnormalities in digestive system once the patient has fasted and been given a radiopaque substance (barium) to swallow. If it is necessary to examine the small bowel, the barium may be given by inserting the tube through the nose and stomach. *Barium enema* involves the insertion of a small nozzle into the rectum, followed by the insertion of barium into the colon via gravity. The patient then moves position so that X-rays of various views of the colon may be taken. Preparation for the procedure is extensive since the colon must be completely clean. To achieve this different techniques are employed, such as a fluid diet for a day before the test, followed by a magnesium citrate drink, or repeated enemas. *Ultrasound* is a painless procedure, which can be used to examine suspected abscesses, abdominal masses and gallstones. It simply involves applying a lubricated probe to the abdomen, though fasting is required. *CT scans* provide cross-sectional views of the body and are used primarily to detect abscesses in CD.

Other investigations frequently carried out during an acute attack of IBD include blood and stool tests.

2.4.2 Drug therapy

The nature of the drug therapy given to patients varies according to diagnosis and severity of symptoms. The most common forms of treatment are corticosteroids and 5-aminosalicylic acid (5-ASA) drugs.

Corticosteroids inhibit inflammatory pathways, thus bringing about fast and effective relief from symptoms (Rowlinson, 1999). In active CD disease, steroids are considered to the most effective form of treatment, with about 70 per cent of patients responding within four weeks (Rampton, 1999). Such drugs may be administered intravenously, orally or rectally. Most patients tolerate a short course of such treatment well, but others may suffer weight gain, changes in mood and acne. In the long term, there is also a risk of developing osteoporosis. For this reason, it is important to reduce the dose as soon as the episode is under control.

Sulphasalazine, which consists of 5-ASA linked to a carrier molecule, has been the standard treatment for UC since the 1950s. This acts by limiting the chemical products of inflammation that promote diarrhoea, and aside from relieving symptoms, reduces the chances of having a flare up (Saibil,1996). Unfortunately, it is estimated that 20-40 per cent of patients cannot take this drug due to side effects caused by the carrier, including

headaches, nausea, anorexia, skin rashes. More severe, but rare, reactions include reduced white blood cell and platelet count. In recent years, a new range of 5-ASA drugs have been developed which do not contain this carrier and are therefore better tolerated (Rowlinson, 1999).

Where the disease is resistant to these treatments, immunosuppressive drugs, such as Azathioprine, Methotrexate or Cyclosporine, are used. These are drugs which reduce the body's resistance to infection and other foreign bodies by suppressing the immune system. They are highly toxic and side effects can include nausea, diarrhoea, flu-like symptoms, pancreatitis, hepatitis, hypersensitivity reaction, and leucopenia.

More recently, a new drug - anti-TNFα monoclonal antibody, has been introduced as a treatment for CD, relieving symptoms by blocking the process of inflammation. It acts by neutralising a chemical called tumor necrosis factor alpha (TNFα), which is involved in making the intestine inflamed in CD. In the UK, the National Institute of Clinical Excellence (NICE) recommends that Infliximab – one form of the drug, be prescribed in conditions of severe disease, when immunosuppressants and corticosteroids have failed, and surgery is not possible. Although research has demonstrated that Infliximab can suppress disease activity in the majority of CD patients after only one dose, further research is needed to establish its long term safety and the dose that should be administered. Furthermore, there is a risk of exacerbating underlying tuberculosis (TB), so patients need to be screened for TB prior to receiving the drug.

Infliximab is given by infusion directly into the vein over a two hour period. Since infusion reactions occur in up to 20% of patients, it is administered in hospital where full resuscitation facilities are available. Infliximab is usually given in combination with immunosuppressants in order to prevent the body from developing antibodies that negate the therapeutic value of the drug and cause febrile allergic reaction. Common side effects include headache, nausea, and upper respiratory tract infections. Serious infections, such as salmonella enterocolitis, pneumonia, and cellulitis, have also been reported. The rapid healing brought about by the drug may also precipitate obstructions. (NACC 2002a; NICE 2002; Rampton,1999).

Finally, although there is limited research evidence to support the efficacy of antibiotics in treating IBD, they are often employed in the treatment of active UC and CD, based on the assumption that enteral flora play a role in the cause of symptoms (Podolsky, 2002).

2.4.3 *Dietary therapy*

Due to poor appetite, malabsorption and increased gut loss, patients may be malnourished and need liquid protein supplements, and/or various vitamin and minerals supplements (Rampton, 1999; Rowlinson 1999; Thompson, 1993). Dietary therapy takes two main forms – elemental and non-elemental. Non-elemental diets require some form of digestion before they can be absorbed. Elemental diets contain elements that require little or no digestion, but are more unpalatable. Both forms of diet can be taken orally or through a nasogastric tube into the intestine (otherwise referred to as enteral feeding). Such dietary treatment is often employed in patients with CD. In some CD patients liquid sip feeds may be used for periods of several weeks to the complete exclusion of other foods.

Parenteral nutrition, sometimes referred to as 'bowel rest', is a treatment for acute IBD, which enables healing of the affected areas of the digestive system while treatment is given to control symptoms. Here a simple solution of sodium, chloride and/or glucose is administered intravenously, with vitamins, potassium and other elements added as necessary.

2.4.4 *Surgical interventions*

When medical management fails, or complications develop, surgery is an option for patients with IBD. For patients with UC surgery can be curative, since removal of the colon (colectomy) means it is impossible to have colitis. The decision to perform a colectomy may be elective in patients where the disease becomes severe despite medical treatment. However, it can become imperative where there is a high risk of cancer, or can happen in an emergency situation due to serious complications brought about by the disease. After removing the colon, the open end of the ileum is brought out of the abdominal cavity. At this point, there are a number of options for dealing with the disconnected ileum (the creation of ileorectal anastomosis with retention of the rectum, ileostomy, continent ileostomy, or ileal pouch), but the creation of a 'pouch' is the procedure of choice as it allows the retention of the anus and elimination of waste by the normal route (Thompson, 1993; Rowlinson, 1999).

Surgery for CD can involve the removal of a segment of the bowel (resection); the surgical widening of a stricture in the bowel or colon (stricturoplasty); and the draining of abscesses via the insertion of a needle (Rowlinson, 1999). However, resection can only

alleviate symptoms for a period of time, since the condition is likely to recur in other sections of the digestive tract (Worley, 1995; Thompson, 1993). For this reason, surgeons are cautious about removal of affected parts of the bowel since this may lead to 'short bowel syndrome'. Here the intestine is unable to handle nutrients and its own secretions. This usually occurs when there is less than 200cm of bowel left, or when the remaining bowel is unable to function because of severe inflammation.

In summary, while developments in the medical treatment of IBD have brought about substantial improvements in patients' quality of life by helping to control symptoms and improve long-term prognosis, this treatment may in itself have a negative impact on patients as much of it is highly invasive and unpleasant side-effects are possible.

2.5 Fertility And Pregnancy

In males with IBD, fertility is reported to be no different than for the general population, but the drug Sulphasalazine reduces sperm counts and motility (Forbes, 1997; Williams, 1999). In females it is thought fertility rates may be normal, but fewer children are born to women with CD (Forbes, 1997; Mayberry and Weterman, 1986). It remains unclear whether this is due to difficulties conceiving, medical advice, or a choice that women make due to problems coping with the condition (Forbes, 1997). A survey of young women with CD did find that up to 50 per cent reduced or abstained from sexual activity for fear of faecal incontinence, abdominal pain or painful intercourse (Moody and Mayberry, 1993). It is also worth noting that the menopause occurs about four years earlier in women with CD than in the general population (Forbes, 1997). The impact of UC on birth rates is unclear due to lack of research in the area.

In relation to the impact of pregnancy on disease activity, Forbes (1997) suggests that around half of women with IBD find that they are at their best during pregnancy, while in about 10-15 percent the bowel is more troublesome than before, and a small number of women present with the condition for the first time (Forbes, 1997). He also reports that just after the birth is a peak time for relapse in both UC and CD, and recommends routinely booking patients in for an appointment 2- 4 weeks after the expected date of delivery (Forbes, 1997).

It is often difficult to offer firm advice regarding the use of medication during pregnancy because IBD medication is almost never tested on pregnant women prior to it being marketed. As a result, conclusions have to be drawn from post marketing surveillance

and animal based studies (Williams, 1999), and views on the use of medication during this period are mixed. For example, Forbes (1997) advises that the newer 5-ASAs can be taken during pregnancy, but that steroids and immunosuppressants should be avoided whenever possible. Others suggest that most drugs, including immunospressants, are safe and it wiser to use them to avoid the disease being active and the possibility of surgical intervention (Korelitz, 1998).

In general, IBD does not pose a risk to the foetus. Birth weights, rates of spontaneous abortions, and malformations are no different from the general population (Williams, 1999). However, flare-ups in the condition do increase the likelihood of a premature birth, and the baby having a low birth weight. In cases where the flare up is very severe, the survival of the foetus may be at risk (NACC, 2002b). Therefore, it is important that every effort is made to keep the disease under control during this time. With regard to giving birth, women who have active perianal Crohn's, or have had surgery for anorectal fistula, are strongly recommended to have a caesarean section (Forbes, 1997).

After the birth, it advised that women taking immunosuppressives may wish to bottle-feed their infant, or stop taking the drug, since large quantities of the drug pass to the infant through the milk (Nielsen *et al.*, 2001).

2.6 The Impact Of IBD On Quality Of Life

The impact of IBD on quality of life has been assessed using objectives indices of role functioning (e.g. employment, marital status etc.), as well as the more subjective health - related quality of life (HRQoL) measures. Studies using objective measures suggest patients are managing 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. Mayberry and colleagues found that significantly more patients with CD had experienced long-term unemployment than in the community sample, and 30 per cent were actively concealing their illness from their employer. In the UK, a survey of NACC members (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 had changed their job as a result of the illness.

Despite functioning relatively well in many areas of life, research suggests patients with IBD have high levels of perceived stress and social strain. In Denmark, 106 patients with CD were compared with an age and sex matched control group of healthy patients admitted to hospital for an acute illness and found to have similar family, social, and professional circumstances. Nevertheless, 54 per cent of the patients with CD felt exacerbations of their disease strained their social and professional life (Sorenson, *et al.*, 1987). This highlights the importance of assessing the impact of IBD on everyday life from the patient's perspective, and a large number of researchers have done this using HRQoL measures.

HRQoL encompasses the physical, social, emotional attitudes, and behaviours of an individual (Borkgaonkar and Irvine, 2000). General HRQoL measures enable comparison with healthy controls and patients with other diseases. Based on responses to such measures, HRQoL has been found to be impaired in people with IBD compared to those who are healthy, but good when compared to patients with other chronic conditions (Drossman, *et al.,* 1989; Patrick and Deyo, 1989). Both patients with UC and CD were found to have less dysfunction than people receiving treatment for end-stage, in-centre, hemodialysis, rheumatoid arthritis (RA), chronic back pain and physically disabled adults (Patrick and Deyo, 1989). Quality of life scores for patients with UC were similar to those who have moderate obesity or myocardial infarction. In patients with CD, scores were similar to those with symptomatic angina and hypothyroidism (Drossman *et al.*, 1991b).

When dimensions of generic HRQoL measures were examined separately, the profile was quite distinctive in that, unlike most other chronic conditions, it was the social and emotional aspects of IBD patients' everyday life that were affected rather than physical functioning (ambulation, mobility, and movement) (Hjortswang, *et al.*, 1999; Drossman, *et al.*, 1991b; Drossman *et al.* 1989). This pattern of findings is not surprising given the social stigma associated with many of the symptoms of IBD. As mentioned in Chapter 1, some people are so embarrassed by the symptoms of IBD that they attempt to conceal their illness (Kelly, 1992). Further evidence that such issues are of concern to people with IBD is discussed later in this chapter (see section 2.7.1).

Over the last twenty years, a number of disease specific quality of life measures have been developed, which have the advantage of tapping into the special states and

concerns of patients with IBD (Drossman, *et al.*, 1989). The most popular is the Inflammatory Bowel Disease Questionnaire (IBDQ), which assesses bowel, systemic, social and emotional functioning. Work to develop the IBDQ revealed that the most frequently reported difficulties were in relation to physical symptoms (loose stools, abdominal pain and rectal bleeding), and that systemic functioning, which includes symptoms such as fatigue, difficulty sleeping, and maintaining weight, was more affected than emotional and social functioning (Mitchell *et al.*, 1988).

Although there is now a considerable body of evidence to indicate that disease activity is one of the main determinants of HRQoL, and that patients with CD have worse HRQoL than those with UC due to greater symptomatology, it is widely recognised that disease activity *alone* does not predict a patient's sense of well-being (Cohen, 2002; Borgaonkar and Irvine, 2000; Casati *et al.*, 2000; Drossman,1998; Drossman *et al.*, 1989; Hjortswang *et al*, 1999). In a number of studies, worries and concerns have been found to be a better predictor of HRQoL than disease activity (de Rooy *et al.*, 2001; Hjortswang, *et al.*, 1999; Drossman *et al.*, 1991a), and recent research has found psychiatric symptoms are a significant predictor of HRQoL after taking disease activity into account (Guthrie *et al.*, 2002; Walker *et al.*,1996; Turnbull and Vallis, 1995). However, although it is hypothesised by researchers who have carried out these studies that psychological distress leads to impaired HRQoL, all the studies are cross-sectional, and it is equally possible that poor quality of life causes psychological distress.

Other predictors of quality of life given less research attention include coping strategies, social support and sociodemographic variables. In relation to coping, 'emotion-focussed' strategies were associated with decreased perceptions of health, well-being and functioning in two studies concerned with coping with the condition in general (Smolen and Topp, 1998, Kinash *et al.*, 1993). In a study specific to patients who had undergone surgery, the emotion-focussed coping strategies 'self-blame' and 'escape-avoidance' - were negatively associated with HRQoL (Maunder and Esplen, 1999). However in a later study, after controlling for coping style and physical symptoms, a further 12 per cent of the variance in quality of life was accounted for by social support (Maunder and Esplen, 1999). With regard to sociodemographic variables, one study has found education and gender are significant predictors of HRQoL after controlling for disease activity, with higher level of education and male gender predicting better scores (Casellas *et al.*, 2002).

2.7 IBD And Psychological Well-Being

There are two main strands to research into the psychological well-being of people with IBD. First, there is a long history of research into psychiatric symptoms in patients with IBD. Early reports, dating back to the 1930s, were highly dubious, being based on one or two case studies of individuals with UC undergoing psychotherapy (North *et al.*, 1990), and were driven by the search for a psychosomatic basis for IBD. In recent years, the quality of the research has slowly improved, and there has been a focus on clearly establishing if prevalence of anxiety and depression is any greater than in the general population, and whether psychiatric symptoms are precursors to, or the result of, IBD.

Second, in recent years an interest in the nature of patients' worries and concerns has also emerged. This seems to have been stimulated in part by the development of a self-report measure - The Rating Form of IBD Patient Concerns (RFIPC) (Drossman *et al.*, 1991a).

Both strands of research are reviewed below. Given that research into worries and concerns might help explain why people with IBD experience anxiety and depression, it will be reviewed first.

2.7.1 The nature of patients' worries and concerns

In 2000, Casati and colleagues reviewed the research into the worries and concerns of people with IBD and identified eight major themes (Casati *et al.*, 2000). The most prevalent concern was lack of energy. Others were: the sense of lack of control; body image (which can be altered by medication and surgery); isolation and fear, due to both the embarrassing and unpredictable nature of the condition, and the possibility of developing colon or bowel cancer; feeling a burden on others; feeling dirty; and lack of information from the medical community. The reviewers 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.

Much of the research reviewed by Casati and colleagues was Canadian, and recent research has found there are cross-cultural variations in the issues that concern patients (Levenstein *et al.*, 2001). Therefore, for the purposes of this thesis, it is important to consider the specific concerns of people in the UK. In a survey of a random sample of

2400 members of NACC in the UK (Walters, 2000), respondents were asked what aspect of their condition caused them greatest concern. Many of the worries reported were similar to, or seemed to relate to, those identified by Casati *et al.*, (2000): for example, unpredictability of relapse, cancer, incontinence, effects on the family, fear of dependency, inability to socialise. In addition, concerns about deterioration, surgery, the incurable nature of the condition, lifelong treatment and its side effects, difficulty planning for the future, using strange toilets, and problems keeping on weight emerged. The author concluded that uncertainty associated with the condition, both in the short term (relapses, finding toilets) and in the longer term (uncertain prognosis, cancer) impacts on quality of life and causes underlying worry.

In a number of studies, comparisons have been made between sub-groups of people with IBD. UC patients report being significantly more concerned about loss of bowel control and developing cancer than CD patients, whereas CD patients are significantly more concerned about ability to have children and having pain (Drossman *et al.*, 1989). In a comparison of male and female patients, analysis of variance found that, after correcting for perceived health status, women were more concerned than men about feelings about one's body, attractiveness, feeling alone, and having children (Maunder and Esplen, 1999). 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.

Finally, it is worth noting that higher levels of concern, as assessed by RFIPC, are associated with greater disease severity, female gender, and lower educational status (Maunder *et al.*, 1999; Maunder *et al.*, 1997; Drossman *et. al,* 1991a).

2.7.2 The prevalence of anxiety and depression

Various groups of researchers have reviewed the literature into the prevalence of psychiatric problems in patients with IBD (Searle and Bennet, 2001; Schwartz and Blanchard, 1990; North *et al* 1990; North and Alpers, 1994) and, in all cases, the poor quality of the research hampered the conclusions that could be drawn. The long list of flaws include the wide range of psychosocial variables measured, making comparisons between studies difficult; problems with sampling (small number of subjects, gastrointestinal disease not adequately confirmed, specific diagnosis of IBD not stated,

non-random or biased selection); lack of, or inadequate, control groups; and data analysis either not carried out or not described. North *et al.* (1990) noted particular difficulties with research prior to 1970s since standardised diagnostic criteria for psychiatric disorder only became available at this point. Nevertheless, Schwarz and Blanchard (1990) and North *et al.* (1990) conclude that the evidence suggests there is no association between UC and psychiatric disorder. North notes that rates of psychiatric disorder are similar to that found in populations without an illness (25-34%). Schwarz and Blanchard point out that psychopathology is comparable to other chronically ill groups.

Conclusions regarding CD have changed over time as more studies have been undertaken. In 1990, Schwarz and Blanchard found that, although many researchers reported elevated levels of depression, anxiety, and neuroses in patients with CD, others did not, and there was no consistent description of the level of psychopathology in CD patients. By the time North reviewed the literature in 1994, the evidence was beginning to point to elevated psychological distress in patients with CD, with major depression prevalent in between 19 and 36% of CD patients, and anxiety in between 2 and 42% of samples. In the majority of studies comparing UC and CD, prevalence was higher in CD. As in research into quality of life, recent studies suggest the greater difficulties experienced by patients with CD is due to more symptomatology (Guthrie *et al.*, 2002; Nordin, *et al.*, 2002; Drossman, 1991b).

Within the Schwarz and Blanchard's review, one study was highlighted as particularly noteworthy. Andrews *et al.* (1987) compared patients with CD who were ill with those in remission, and found a substantially higher level of psychiatric illness in the physically ill group (50% versus 8%). Based on these findings, Schwarz and Blanchard recommended that future research look beyond diagnosis, to consider the level of disease activity in patients. Following on from this, Searle and Bennet (2001) reviewed research published between 1990 and 2000 to establish if there is a link between disease activity and distress and, if so, the direction of causality. They found just six studies on the issue, and four were by the same author reporting on different aspects of a single study. Some simply provide cross-sectional evidence of an association between disease activity and depression. However, Porcelli and colleagues (1996) followed 104 patients over six months, and found the clinical course of the IBD was strongly associated with anxiety ($F=3.67$, $p=<.001$) and mildly with depression ($F=3.67$, $p=.03$), with an improvement in the condition related to a reduction in anxiety scores. In a small scale study of 25 UC patients (Angelopoulos, *et al.*, 1996), anxiety and depression were significantly higher in patients in

an active phase compared to those in an inactive phase, and level of distress decreased while in remission.

Since Searle and Bennet's review, further evidence that IBD leads to anxiety and depression has emerged. Kurina and colleagues (2001) examined a large scale database of records of hospital admissions in the UK between 1963 and 1999, and found the relative risks of having UC after a psychiatric condition were small (1.4 for depression and 1.5 for anxiety), and there was no increase in the risk of having CD. In contrast to this, when the likelihood of IBD being *followed* by a psychiatric condition was examined, both depression and anxiety were significantly more common after diagnosis of CD compared to controls (a five-fold increase in risk in the year after diagnosis), and UC was followed by anxiety more often than expected by chance (four-fold increase in risk in the first year post diagnosis).

With the focus of attention in recent years being on the relationship between disease activity and psychological distress, little attention has been given to other factors that might influence distress. However, Sewitch *et al.* (2001) examined the role of social support in relation to psychological distress. Regression analysis revealed that active disease, shorter time since diagnosis, greater number and impact of recent minor stressful events, were all significant predictors of distress. There was also an interaction between perceived stress and social support. Patients who were more satisfied with social support were less vulnerable to distress when confronted with moderate to high perceived stress. Thus the findings support the stress-buffering theory of social support, and the authors conclude that strategies to reduce perceived stress and improve social support may be beneficial to the patient.

2.8 Reflections On The Implications For Parents

In summary, while the evidence suggests that the physical functioning of people with IBD is relatively good compared with those with other chronic illnesses, IBD clearly impacts on a number of aspects of everyday life and is likely to have implications for parents. Parents with IBD are likely to experience pain and have less energy than parents who have no health problems. Medical treatment and investigations may involve invasive procedures, result in unpleasant side-effects, lead to periods of time away from home, and disrupt the family routine. Families' social activities may be restricted through the need for the parent with IBD to be near toilet facilities. There may be financial difficulties for some due to the

need for the parent with IBD to give up work, change jobs, or work part-time. Parents may also have a number of worries and concerns about their health, and experience depression and/or anxiety. Finally, some may feel the need to conceal their illness from others due to the social stigma associated with symptoms, so putting themselves under further strain.

While all these effects are possible, the research also points to considerable variation in the impact that IBD has on parents. Clearly disease activity will influence the extent to which parents experience the aforementioned problems. However, the research evidence also suggests variation amongst those experiencing symptoms of a similar severity. If the pattern of results found in studies of HRQoL and psychological distress are repeated in those who are parents, it seems likely that experiences will vary according to how much parents worry about their health, the coping strategies they employ, their sociodemographic background, and the support available to them. Furthermore, not only will there be differences between parents, but individual parent's experiences will fluctuate over time, as they move in and out of remission.

CHAPTER 3

Theoretical Perspectives

3.1 Introduction

In order to develop hypotheses about the impact of IBD on parents and their children, and how best to approach research concerned with their support needs, this thesis draws upon three theoretical frameworks. The framework underpinning the research is the transactional model of stress and coping (Lazarus, 1999; Lazarus and Folkman, 1984). This has been supplemented by the family-systems illness model (Rolland, 1999; 1984), and the resource-based approach to intervention (Dunst *et al.* 1988). In this chapter these frameworks are described in turn, with a particular focus on aspects relevant to parents with IBD and their children. All theories have shortcomings and, in applying a framework, it is important to be aware of these so as not to apply too much weight on aspects that are problematic. For this reason, the common criticisms of each theory are described. Next the implications of the theory for research with parents with IBD and their children are discussed. Finally, the chapter ends with a summary of how the frameworks have influenced the research design and methods employed in this thesis.

3.2 The Transactional Model Of Stress And Coping

A diverse range of theories, drawn from different academic disciplines, have attempted to explain the impact of stressors on individuals and the development of stress-related problems. The transactional theory of stress and coping (for example, Lazarus, 2000; Lazarus, 1999; Lazarus and Folkman, 1984) is a psychological theory and, as such, focuses on the cognitive strategies that explain the perception, experience, interpretation, and resulting effects of stress. Being a general model of stress and coping, it can be applied to any potentially stressful situation. The central feature of this theory is the importance of appraisal: nothing can be labelled as stressful unless it is appraised as such by the individual. This means that stress does not exist in the 'event', but as the result of the transaction between a person and his or her environment (Lyon, 2000).

According to Lazarus, 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). 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. If the answer is 'yes', then the person appraises whether the situation is harmful (damage has already occurred), threatening (there is a possibility of damage), or challenging (the situation needs to be dealt with but the individual feels enthusiastic or optimistic about his/her ability to deal with it). Threat and challenge can both occur in the same situation, but one is likely to predominate. Recently Lazarus extended the theory by adding a fourth type of appraisal – benefit, which leads to positively toned emotions (Lazarus, 1999).

Once a situation has been appraised as involving harm, threat or challenge, the individual decides what to do about the situation. This is *secondary appraisal*, when various coping options are evaluated, and a decision is made as to which ones to use. There is always an interplay between the two types of appraising since secondary appraising is needed to fully understand one's plight.

In this model, coping refers to efforts to master, reduce or tolerate the demands of the situation; there is no assumption that these actions will be effective. The characteristics and demands of the situation influence appraisal and the coping strategy adopted, but resources also play an important role, determining both how the individual appraises the situation and the coping options available to him/her. 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.

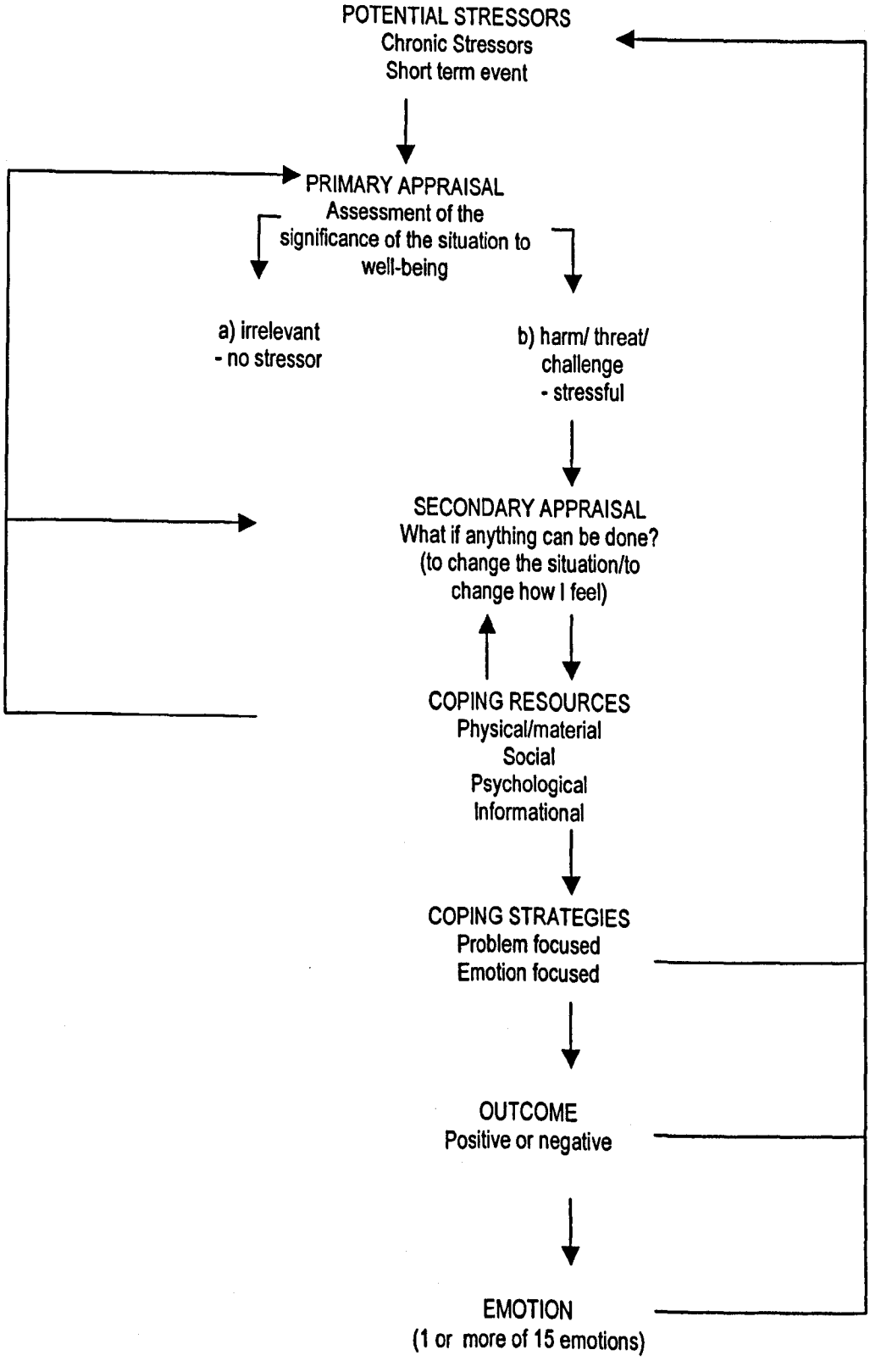
Coping strategies can be broadly categorised as efforts to reduce or regulate stressful emotions (emotion-focussed coping), and to alter the stressful situation (problem-focussed coping). Research on coping indicates that often both types of coping are used together (Folkman and Lazarus, 1985). The efficacy of a coping strategy depends on the type of person, the threat, the stage of the stressful encounter, and outcome under consideration. This means there is no universal adaptive coping strategy. However, some specific

hypotheses have been developed about effective coping with controllable and uncontrollable situations. As discussed in Chapters 1 and 2, people with IBD experience a great deal of uncertainty both in their day to day life, due to the fluctuating nature of the symptoms, and in the long term, with regard to their prognosis. Therefore coping with uncontrollable events is of particular interest to this thesis. Folkman (1984) proposed that, when a situation is realistically appraised as uncontrollable, reappraisal and cognitive coping could prevent negative feelings even in the face of considerable uncontrollability. However, when a person appraises a situation as controllable when it is not, they are likely to try to use problem-focused strategies, which will be unsuccessful, and they will then become frustrated and disappointed.

Together the appraisal and coping process mediate the emotional reaction. Fifteen different emotions are specified, though Lazarus acknowledges this list may not be exhaustive (Lazarus, 2000). 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.

In summary, the theory suggests that the outcome of coping is dependent upon a multiplicity of factors, and events that appear similar on the surface can differ considerably in their impact on individuals. Figure 1 provides an overview of the process.

Figure 1: Model of the stress and coping process, Lazarus (1999)



As illustrated by Figure 1, Lazarus and Folkman's theory is transactional. Here the relationship between the person and environment is viewed as a dynamic constantly changing process, which involves extensive psychological mediational and reciprocal feedback loops (Bartlett, 1998). From a transactional perspective, it is not possible to designate certain variables as coming first, and others as being determined by them, since these variables will change according to the point in the process you choose to examine. Therefore, in order to find statistical evidence to support the theory, it is necessary to develop and test complex models based on a systems perspective. Lazarus suggests this is rarely practical, and instead advocates the use of narrative methodologies, particularly as such an approach provides an insight into the person-environment relationship, as construed by the person (Lazarus, 1999).

In recent publications, Lazarus has distinguished between acute and chronic stress:

> *Chronic stress arises from harmful or threatening, but stable, conditions of life, and from stressful roles people continuously fulfil at work and in the family. Acute stress, conversely, is provoked by time-limited, major or minor events that are harmful or threatening at a particular moment in life, or for a relatively brief period.* (Lazarus, 1999: 144)

However, Lazarus acknowledges that it is often difficult to distinguish between the two types of stress since major events often lead to new sources of chronic or daily stress.

As chronic stress is often part of the fabric of everyday life, it can go unacknowledged by the person experiencing it, or by those around them. Lazarus urges researchers not to overlook such stressors since they are highly significant for people's well-being. In his own research during the 1980s, daily hassles were found to have a greater impact on negative health outcomes than major life events, a finding which has since been replicated by many other researchers (see Macnee and McCabe, 2000, for a review).

When applying the framework to children, it is important to be aware that basic features of cognitive and social development may affect the stress and coping process. First, the way in which a child perceives a stressful situation may be different from that of an adult (Compas, 1987). Children's ability to differentiate between situations that are controllable and uncontrollable has been found to increase with age (Band and Weisz, 1988; Harris, 1989). In addition, the self-concepts of adolescents may be more easily threatened than those of younger children, since the ability to make meaningful social comparison and

internalise negative experiences increases with age (Fields and Prinz, 1997; Thompson, 1990).

Development may also affect the strategies children apply to a situation. Studies of coping in children and adolescents suggest that problem-focused skills emerge first, appearing by the preschool years. Emotion-focused emerge later in childhood and continue to develop until early adolescence. Specifity of coping according to the type of stressor also increases with age (Fields and Prinz, 1997; Compas, *et al.,* 1991).

Finally, children's environments are quite different to those of adults because they have less control over their circumstances, thus limiting the coping strategies available to them (Fields and Prinz, 1997). However, children aged between 6 and 8 years tend to overestimate their own influence over events, and therefore may persist in making efforts to alter a situation that is beyond their control (Compas *et al.*,1991).

There is now a very large body of research on child and adolescent resilience and invulnerability to stress, which suggests resources that are particularly pertinent to children. Based on a review of longitudinal studies published since the mid-1980's, involving children from different geographic regions of the United States, exposed to different risk factors, a set of protective factors which seem to transcend the nature of the stress experienced, as well as ethnic, social class, and geographic boundaries, have been identified (Werner, 2000). These protective factors are as follows:

- Factors within the child
  - having at least average intelligence;
  - positive temperamental characteristics;
- Factors within the family
  - the opportunity to establish a close bond with at least one person who provides stable and appropriate care during the first year of life ;
  - indicators of maternal competence, such as educational level and gainful employment ;
  - nurturing from alternative caregivers in families in which a parent is absent or incapacitated;
  - socialisation practices within the family ;
  - taking on domestic responsibility and part-time work ;
  - the family holding religious beliefs;

- Factors within the community
  - being liked by members of your peer group;
  - having one or more close friend;
  - enjoying school ;
  - putting abilities to good use ;
  - having a supportive teacher.

3.2.1 Criticisms and shortfalls of the framework

The transactional theory of stress and coping has been criticised for a number of reasons. First, there is concern that too much weight is placed on the internal processes that shape an individual's response to stress (Coyne and Smith, 1991). However Lazarus and colleagues do make it clear that the stress and coping process is influenced by a wide range of resources within the socio-ecological environment, so this criticism may apply more to the way researchers have chosen to apply the theory than to the theory per se. Second, no one theory of stress deals with every aspect of the process and this theory does not elaborate on the physiological mechanism of the stress process (Barlett, 1998). Third, it is very difficult to test the concept of appraisal empirically since Lazarus suggests appraisal is sometimes unconscious, automatic and instantaneous and, as a result, it is not always possible to obtain self-reports of appraisals (Bartlett, 1998).

In relation to research guided by the theory, there is concern that, despite a large amount of research activity, we are unable to draw conclusions about which coping strategies are helpful to people with chronic illnesses (De Ridder and Schreurs, 1996). However, this may to some extent reflect research design, with recent research suggesting that it is not the nature of coping, but the number of attempts that are made which is important, and that more significant effects would be found if researchers assessed outcome measures closely related to the coping efforts, rather than the distal parameters of well-being, such as depression (De Ridder and Schreurs, 1996). In addition, research into coping has tended to involve the use of standardised checklists, which have been criticised for a wide number of reasons, including data not being collected on the type of stressor people are reporting on; items describing the coping strategy being vaguely worded; people responding positively to coping strategies they have used in the past, but not used in the situation being described; responses being unreliable due to recall error; and people not endorsing items they know are frowned upon (Lazarus, 1999; Somerfield, 1997a,b;Coyne & Gottlieb,1996). In summary, it seems that a large proportion of the criticisms levelled

at the transactional theory of stress and coping are due to the way research guided by the theory has been carried out, rather than the theory per se.

3.2.2 Implications for parents with IBD and their children

It is clear from the above discussion that, in adopting this framework, care is needed in designing the study, selecting methods, and analysing results. Qualitative research is most appropriate, enabling us to gain an understanding of what having IBD means to parents and their children, which aspects of the experience are perceived as harmful, threatening, challenging and beneficial and why, and the resources individuals draw upon to manage stressors.

The theory suggests a number of factors which determine whether IBD is stressful to parents and children, and influence how they might go about coping. For instance, symptoms of IBD may limit a parent's 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. 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, difficulties caring for the child may not be as stressful if childcare 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 the parent is not the child's main carer. In this case, no coping efforts will be needed.

In relation to children who have a parent with IBD, the child's response to parental illness will also be determined by how they appraise it and the resources they have available for coping. The appraisal is likely to be influenced by the extent to which the illness limits the parent's ability to care for them, but also by general perceptions of whether the illness is threatening to the parent in the long term. Age differences in appraisals are to be expected since the extent to which children are dependent on the parent decreases as they grow older. As for adults, resources will influence appraisal. In particular, if the child

or adolescent has alternative caregivers who they can turn for emotional support and care, the situation is much less likely to be viewed as threatening or damaging.

Given that IBD is a chronic condition, it is likely that many of the stressful experiences it causes may be persistent. However, it is also possible that acute events, such as hospitalisation for a flare up, may exacerbate these chronic experiences.

3.3 The Family Systems-Illness Model

The family systems-illness model (Rolland, 1999; 1984) combines aspects of family systems theory, with a typology of illness characteristics. This produces a model aimed at explaining variability in the stress experienced by families in response to illness in a family member. The 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. It is proposed that the psychosocial demands an illness places on the patient and their families will vary according to the 'onset', 'course', 'outcome', 'incapacitation' and the 'level of uncertainty' about its trajectory.

Onset – is concerned with different types of symptomatic presentation and can be either acute or gradual. Acute onset is said to place greater strain on the family as they attempt to utilise their resources to protect against further damage, and make efforts to master the situation. Gradual onset allows for a protracted period of adjustment, but may cause anxiety through uncertain diagnosis.

Course - is concerned with whether the condition is progressive, constant, or relapsing. In a progressive illness, caretakers risk becoming exhausted since periods of relief from the illness are minimal and care taking demands tend to increase over time. In constant illnesses, the family is faced with a semi-permanent change that is stable and predictable over a considerable period of time, but family exhaustion is possible through the strain of the new role demands over time. Relapsing or episodic illness are characterised by periods of absence, or low levels, of symptoms, followed by periods of flare-up or exacerbation. Often the family can carry on a normal routine, but the possibility of recurrence hangs over their head. This type of illness is said to require the least ongoing care taking or role reallocation, but strain in the family is caused by the frequency of transition between crisis and non-crisis, and the ongoing uncertainty of when a crisis will

occur. Rolland suggests that the unpredictability of an illness is one of the most significant sources of strain for families, hindering plans for the future.

Outcome – is the extent to which the illness is likely to cause death or shorten one's life span. It is hypothesized that the most crucial factor is the initial expectation of whether a disease is likely to cause death. The outcomes of illnesses are conceived as lying on a continuum: at one extreme are illnesses that do not typically affect the life span, at the other are those that are clearly progressive and usually fatal. For families in which there is a life-threatening illness, there exists an undercurrent of anticipatory grief and separation.

Incapacitation - is the extent to which an illness causes impairment of cognition, sensation, movement, energy production, or disfigurement. The level of incapacitation is said to be a highly significant factor determining the level of stress experienced by the family. The sum effect of incapacitation on an individual or family depends on the interaction between the type of incapacitation with the pre-illness roles occupied by the ill member.

In addition to the characteristics of the illness, the model highlights the importance of considering the life cycle of the illness, which consists of three major phases: crisis, chronic, and terminal. The crisis phase includes the symptomatic period before actual diagnosis and the initial period of readjustment after diagnosis. The chronic phase is the period in which the family has adjusted to the illness and is concerned with getting on with day-to-day life. The terminal phase occurs in illnesses which are life-limiting, and includes the pre-terminal stage, where the inevitability of death becomes apparent and predominates family life, and the periods of mourning and loss resolution.

Finally, the demands an illness places on a family are said to vary according to the stage of the family life cycle. Greatest difficulty is experienced when a chronic illness develops during the child rearing years, making it more difficult to meet both individual and family goals, and when care-giving resources must be juggled between the children and the ill parent.

3.3.1 Criticisms and shortfalls of the framework

This framework is based on family systems theory, in which theorists argue that rather than a chronic illness only influencing an individual, it influences the family system. The

family system refers to a group of individuals and the pattern of relationships between them. Furthermore, not only is the family profoundly affected by the chronic illness, but the family's response to this challenge has a profound effect on the development and well-being of the person with the chronic illness and, in many cases, on the course of the illness itself (Patterson and Garwick, 1994). An implication of conceiving of the family as a 'system', is that a change on one part of the system can bring about a change in another part of the system. Therefore, it is argued that services caring for people with a chronic illness should work with the whole family if they wish to bring about change.

The appeal of family systems theory in general is that it is a positive framework for research and service delivery aimed at families, since families' relationships are conceived of as a resource (Rolland, 1999; Cheal, 1991). However, family systems theories have been criticised at a number of levels. First, within the therapeutic context, for assuming that maintenance of the family system is a positive thing. Secondly, it has also been argued, particularly by feminist researchers, that it overlooks the individual concerns of family members. Thirdly, by focusing on relationships within the family, little attention is paid to how social context shapes family life, and the role of the family in determining outcomes for individuals is given undue weight (Cheal, 1991; Coyne and Smith, 1991, Pam 1993). Finally, much research which claims to be based on a family systems perspective fails to elicit data from all members of the family. More specifically, the focus is often on gathering parents' views, rather than those of the child (see Patterson and Garwick 1994 for examples), an approach which parallels what tends to happen within family therapy (Sayger, 2001).

3.3.2 Implications for parents with IBD and their children

The family systems-illness model highlights aspects of IBD which are likely to place psychosocial demands on the patient and his/her family, and which may differentiate it from other chronic conditions. For people with IBD, onset of the condition may be acute or gradual. Incapacitation will be in relation to energy and social stigma. For those who have had surgery there is also the possibility of disfigurement. In addition, feeling that they need to be near to toilet facilities during flare-ups may restrict patients' movements. 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, and make it difficult to plan for the future. However, there may be less need for role reallocation than in families dealing with some other conditions. IBD does

not typically affect life-span, but long term prognosis may be a source of uncertainty for patients and their family.

When investigating the experiences of parents and their families, the theory suggests attention should be paid to the age of children within the family and how long the patient has been diagnosed with the condition. Greatest stress is likely in families with younger children, and in the period before and immediately after diagnosis.

3.4 The Resource-Based Approach To Intervention

Based on social and family systems theory, as well as numerous empirical investigations, Dunst and colleagues have developed a conceptual and programmatic framework for helping families identify and meet their needs in a way that is both enabling and empowering (Dunst *et al.* 1988). It is rooted in four basic principles, all of which are based on research evidence. These principles are as follows:

1. The greatest impact on child, parent, and family functioning is most likely to occur when interventions are based on the needs, aspirations, and personal projects a family considers important enough to devote its time and energy to.
2. People are more likely to be successful in efforts to reach aspirations and meet needs if we strengthen and support the things a family already does well as a basis for mobilizing resources.
3. Informal support networks are a primary source of resources for meeting needs and one should build upon and strengthen natural support systems as a major way of meeting needs.
4. The family's use and acquisition of competencies for mobilizing resources are most likely to occur when professionals employ behaviours that create opportunities for family members to display or become better able to meet their needs.

Clearly, the framework is primarily a guide for practitioners working directly with families. However, a number of aspects of the framework are useful for research which aims to clarify what support is needed by families in which a parent has a chronic illness. This includes their conceptualisation of support needs and family resources. Support needs are defined as follows:

A need is something (e.g. a resource) that is desired or lacking but wanted or required to achieve a goal or attain a particular end. Operationally, a need is an individual's judgement of the discrepancy between actual states or conditions and what is considered normative, desired, or valued from a help seeker's and not a help giver's perspective. Unless there is an indicated need for a resource on the part of a help seeker, there may not be a need regardless of what a professional believes to be the case. (Dunst *et al.*, 1988: 13)

In relation to resources, Dunst *et al.*, (1988) proposes that a distinction is made between intrafamily and extrafamily resources. The *intrafamily* resources are the existing strengths and capabilities that exist within the family, as well as capacity to use these strengths to create resources necessary to meet these needs. *Extrafamily* resources include the emotional, physical, informational, instrumental and material aid and assistance provided by others. Extrafamily resources may be provided by informal (friends, acquaintances, and social groups) or formal support networks (professionals and agencies).

Dunst warns that the availability of support is not in itself sufficient for families to utilize it, noting that a number of qualitative features of support influence the likelihood that families will mobilize resources for meeting needs. These are listed in table 2.

Table 2: Factors that influence utilization of support, Dunst et al. (1988)

Factor	**Definition**
Response costs	Extent to which the costs of seeking and accepting help outweigh the benefits.
Dependability	Extent to which the family can depend on network members in times of need, and how willing network members are in terms of providing aid and assistance.
Indebtedness	Extent to which help giving by network members creates a personal or psychological sense of obligation.
Reciprocity	Extent to which the exchange of favours is sanctioned or approved but not expected.
Satisfaction	Extent to which one is satisfied with help that is provided by network members.

There are overlaps here with stress and coping theory, which suggests that a person's decision to adopt a particular coping strategy is dependant on their appraisal of the likely outcome.

3.4.1 Criticisms and shortfalls of the framework

First, given that the resource-based approach to intervention is based on family systems theory, the criticisms described in 3.3.1 also apply to this framework. Second, adopting the resource-based approach to intervention means placing central importance on understanding the needs and aspirations of families. However, simply because a service user values an intervention, does not mean that it will be effective. Therefore, gathering parents' and children's views should be treated as necessary and important when developing a family intervention, but not sufficient in itself.

3.4.2 Implications for parents with IBD and their children

Whereas the transactional model of stress and coping, and the family-illness system model, help to formulate hypotheses about the impact of IBD on parents and their children, the resource-based approach to intervention has a different role. In this thesis, where the overall aim is to establish the support needs of parents with IBD and their children, it highlights the importance of gathering parents and children's views on these issues, and reminds us that it is important to be clear both about the *type* of support needed, and *who* might be best placed to provide it.

3.5 Summary Of Implications For This Research

By adopting the transactional model of stress and coping as the theory underpinning the research, this thesis will investigate parents with IBD and their children as two distinct groups, with their own experiences and needs. As advocated by Lazarus, the research will include qualitative methods in order to gain an understanding of what having IBD means to parents with the condition, and their children.

Both the transactional theory of stress and coping, and the family-systems illness model, help answer the question 'Why might some parents and children experience difficulties, while others do not?'. Answering this question will be essential in identifying families most likely to need support from services. Together, the two theories suggest that it is worth exploring whether there are differences in experiences according to:

- Whether the parent is a mother or father
- The parent's and child's perception of the illness
- How long it has been since the parent was diagnosed

- The age of children within the family
- The resources available for coping
- The parent's and child's coping strategies

Finally, while the aforementioned theories help us explore factors likely to influence whether parents and their children need support, the resource-based approach to intervention reminds us to research parents' and children's views on the type of support that should be provided.

CHAPTER 4

The Support Needs of Parents with a Chronic illness and their Children

4.1 Introduction To The Review

Since no previous research has been carried out in relation to parents with IBD or their children, this chapter reviews research carried out on other conditions to gain an insight into the support they are likely to need. This will be addressed by posing the following questions:

- What impact does chronic illness have on parents and on their children?
- What are parents and children's views on the support available to them?
- What support do parents with a chronic illness and their children want from others?

The scope of the review is broad, including research on parents with a physical disability, as this often involves people with a chronic illness. As Champion and Roberts have pointed out:

> *'a chronic illness can cause a physical disability, as in the case of multiple sclerosis and polio. Treatment for an illness also can cause disability (e.g. bone cancer, amputation)*
> (Champion and Roberts, 2001; p 1058).

Although the review includes a broad range of parents, a number of exclusion criteria were adopted to ensure the focus of the review was relevant to this thesis. First, this review is about the *general population* of parents with a chronic illness or disability and their children. Some research about parental illness is based on samples recruited through psychiatric services, family therapy services, young carers projects, or other interventions for families experiencing difficulty. By design, such studies provide a misleading and overly negative impression of the impact of chronic illness on the family and were therefore excluded. Second, this thesis is concerned with families in which there are dependent children living at home; research about families with adult children

was not reviewed. Third, although people with IBD may become severely ill, only very rarely does this lead to their life being at risk. Therefore this review focuses on families dealing with the crisis or chronic, rather than the terminal, phase of an illness. Fourth, research on HIV and AIDS was not reviewed since the experiences of families dealing with this condition are quite distinct, and it is advised that no conclusions be drawn from this literature about the impact of other chronic illnesses (Biggar and Forehand, 1998; Imrie and Coombes, 1996).

As outlined in Chapter 1, this review describes the background to the research. That is, the literature that was available towards the end of 2002, when the final stage of the research was undertaken. This literature helped to shape the nature of the research, and the development of hypotheses about the impact of IBD on parents and their children, including their support needs. Chapter 13 of this thesis includes a discussion of the extent to which the thesis findings fit with existing literature. This discussion includes studies published *after* 2002.

Research published prior to 1980 was excluded from the review. There were a number of reasons for this decision. First, lack of clarity about research design and methods, and methodological flaws, are a feature of many of the studies carried out before 1980 (Kahle and Jones, 1999; Korneluk and Lee, 1998; Worsham *et al.*, 1997; Buck and Hohmann, 1983). Second, it is likely that findings from early research are no longer relevant to parents today since advances in medical treatment mean that life for patients with many conditions has changed considerably in recent years. Third, changes in family structure and societies' expectations regarding the roles and responsibilities of mothers and fathers (Mill *et al.*, 2001; Arendell, 1997), mean that the impact of parental illness on families is likely to have altered since early studies were carried out.

The search strategy used to identify relevant literature is outlined in Appendix 1. The findings from this review are described below in two parts. Part One deals with research on parents' experiences, Part Two with research on the impact of parental illness on children and their support needs. The chapter ends with a summary of the implications for parents with IBD and their children.

4.2 Part One: Research On Parents

Research into the experiences and support needs of parents is dominated by three conditions – cancer, rheumatic diseases (RD) and multiple sclerosis (MS). In addition, a

number of researchers have chosen to work with groups of people with a range of conditions. In some cases studies are described as being about parents with a 'chronic illness', whereas in others researchers refer to 'disabled parents'. However, closer examination reveals that the groups of parents involved in such research are highly similar, and choice of terminology often reveals more about the background of the researcher, than about the research participants.

Research on 'disabled parents' is dominated by academics taking a disability rights perspective, influenced by the social model of disability. They express concern that early research on parents was driven by a search for problems in these families, based on the assumption of negative effects of the parent's disability on their children. They warn that research which sets out to confirm pathologizing hypotheses will succeed in doing so. Thus the cycle of negative assumptions about parents with disabilities is perpetuated (Kirshbaum and Olkin, 2002; Olson, 1996; Wates, 1997).

Research on 'chronic illness' tends to be carried out by those with a nursing or psychology background. Since there is usually a focus on what it is about the nature of the condition that causes difficulties for patients and their families, disability researchers criticise such work for adopting a medical model and failing to explore barriers within the environment. However, these two groups of researchers do have much in common – both are concerned with identifying parents' support needs. The extent to which *any* of the research on parenting has developed our understanding of the support that should be offered to families will be explored in this review.

Before outlining the findings it is important to note that, *most* studies are exploratory, employing qualitative techniques to gather parents' views on the impact their condition has on them and their family. The focus is usually on identifying the difficulties parents' encounter and, as a result, the findings tend to be largely negative. In addition to the qualitative research, there are also a few quantitative studies that assess parental role-functioning, family functioning, or the reallocation of roles within the family. Across both qualitative and quantitative studies it is rare for a comparison group of parents without a chronic illness or disability to be included, so there is usually no way of judging whether the experiences and needs differ from the general population of parents.

Another limitation is that the research tends to represent the experiences of particular sub-groups of parents. For example, the majority of studies focus on mothers, rather than fathers. Where fathers are included, the numbers are sometimes too few to make it

possible to draw conclusions as to whether their experiences differ from those of mothers. In almost every paper the authors point out that the study is based on well-educated, white, middle class parents, and the findings should not be applied to other groups of parents. Many studies are based on parents recruited through voluntary organisations and support groups, so it is not certain that the research is representative of the wider population of people with the condition concerned (Rintala, *et al.*, 2000; Barlow *et al.*, 1999; Association of Disabled Parents in Norfolk, 1996; Goodman, 1992; Smeltzer, 1994; Grimshaw,1992; Crist, 1993). Some papers report difficulties with recruitment, resulting in poor response rates and possible biases in the sample (Smith and Soliday, 2001; Association of Disabled Parents in Norfolk, 1996; Goodman, 1992; Crist, 1993; Friedlander and Viederman, 1982). Occasionally researchers fail to provide any information on how parents were recruited, making it impossible to judge whether the findings are influenced by sampling bias (Thomas, 1999; le Gallez, 1993; Allaire, 1988).

With this note of caution, research on the impact chronic illness on parents is reviewed first. A summary of the studies included in this part of the review, including details of the sample and method of data collection, is provided in Appendix 2. This is followed by research into parents' views on the support available to them, and the support they want from service providers.

4.2.1 What impact does chronic illness have on parents?

As discussed previously, research on the impact of chronic illness on parents is dominated by the difficulties parents' experience. However, where researchers have given parents the opportunity to report on other aspects of their experience, positive effects have emerged. Table 3 provides an overview of both the positive effects and the difficulties. Further details on the findings are given below. This is followed by evidence on factors that seem to influence experiences.

Table 3: The impact of chronic illness on parents - Themes to emerge from the research literature

Difficulties
Dealing with parental responsibilities
Exacerbation of symptoms due to childcare and domestic responsibilities
Restrictions to family social activities
Strain on relationship with child
Knowing how best to explain illness to child
Hospital stays
Financial difficulties for the family
Worries about the future
Dealing with pregnancy
Negative emotional reactions
Positive effects
Spending more time with children
A slower pace of family life
More affectionate towards children
Being a parent encourages coping with the illness
The role of parent is given greater priority

Difficulties experienced by parents with a chronic illness

The most widely reported difficulty for parents is dealing *with parental responsibilities*. Qualitative and quantitative studies involving parents who have cancer, kidney disease (KD), MS, narcolepsy, RD, Spinal Cord Injury (SCI), and a range of chronic illnesses, all report on this issue (Alexander *et al.*, 2002; Smith and Soliday, 2001; Barlow *et al.*, 1999; Fitch *et al.*, 1999; Cassino *et al.*, 1997; Nehring and Cohen, 1995; Blackford, 1995; Ostensen and Rugelsjoen, 1992; Thorne, 1990; Geirdal, 1989; Allaire, 1988; Reisene *et al.*, 1987).

Across these studies, parents have explained that fatigue, pain, mobility problems, and mood swings all serve to make parenting tasks difficult. These tasks include lifting, dressing and bathing, getting up during the night to care for young children, meal preparation, transportation, and housework. In two studies, parents were concerned about not being consistently available for their children (Barlow *et al.*, 1999; Thorne, 1990). Aside from symptoms, dialysis patients have pointed out that the time-consuming nature of the treatment can be a barrier to getting involved with childcare (Smith and Soliday, 2001; Friedlander and Viederman, 1982). Difficulty being involved in the child's school life, as well as getting the child to and from school, have been reported in studies of disabled parents and those with Parkinson's disease (PD) (Grimshaw, 1992; Wates, 1997; Association of Disabled Parents in Norfolk, 1996).

It is important to bear in mind that not *all* parents will experience such difficulties. In a study of mothers with SCI, with access to a high household income, less than 50 per cent said that their disability interfered with child-care tasks (Alexander *et al.*, 2002). Similarly, when mothers with narcolepsy completed a measure of parenting difficulty less than 50 per respondents had moderate to severe difficulty on any one task (Nehring and Cohen, 1995). In Reisine *et al's*, (1987) study of mothers with rheumatoid arthritis (RA), who had children under 13 years of age, 29 per cent said that the condition limited their ability to care for their children in the way they thought they should.

While parents may feel they are struggling to cope with parenting responsibilities, few researchers have compared their parenting with that of parents without an illness. In a rare example of such work, Crist (1993) carried out an observational study of interactions between mothers with MS and their daughters (aged 8-12 years), when asked to complete a play and work task in a laboratory setting. Results were compared with those of a healthy control group. No differences were found between the groups in the extent to which mothers and daughters displayed directive (attempts to command, control or supervise the behaviours of another person), receptive (acceptance or approval of the other person) and dissuasive behaviours (discouraging, disapproving or non-accepting interactions), even though all adaptive devices and independent living aids were removed from mothers with MS during the task. Despite the non-significant findings, many mothers with MS said they took part in the study because they were worried about whether they were being good parents; a reminder that worries about parenting do not necessarily equate to performance. However, it is worth bearing in mind that the study is limited to investigating performance on one measure of parenting – how mothers interact with their child in a laboratory setting. Not only may this not be representative of how mothers interact with their children in everyday life, it may be that the mothers with MS and the control group differ on other aspects of parenting not investigated by the study.

In another study which included a comparison group, responses to a standardised questionnaire indicated that, after controlling for income, parents with SCI did not differ from those without a disability in parenting style (warmth/structure and strictness) (Rintala, *et al.*, 2000). This finding is given further significance when it is considered that warmth/structure was a significant predictor of children's social competence and behaviour problems.

One study has found differences between parents with a chronic illness and a healthly comparison group. Cassino *et al.* (1997) investigated the impact of moderate to severe

asthma on mothers' performance of parenting duties using a quantitative questionnaire. Compared to a case matched control group, significantly more of the mothers with asthma reported that their children had to stay away from home at least once in the previous 12 months, were awakened from sleep at night, were responsible for chores usually performed by their parents, and missed or were regularly late for school. However, both groups of mothers were relatively impoverished, with many receiving welfare and few employed, and it would be unwise to generalise the findings beyond this sample.

Moving on to other issues, while poor health may make parenting difficult to manage, in turn parenting tasks may *increase the parent's health problems.* Mothers with a range of chronic conditions have explained that parenting activities exacerbate fatigue (Thorne, 1990). Studies involving parents with MS and cancer find that mothers often continue with their normal family routine when they want, or have been advised, to rest (Kayser and Sormanti; 2002; Fitch, 1999; Rehm and Catanzaro, 1998; Hilton, 1996). Lack of child care can also mean having to miss rehabilitation appointments (Blackford, 1995).

Restrictions to the frequency, spontaneity, and type of social activities families engage in have been reported by parents with arthritis, KD , MS, PD, and a range of physical disabilities, based predominantly on qualitative research evidence (Smith and Soliday, 2001; Barlow *et al.*, 1999; Rehm and Catanzaro,1998; Wates, 1997; Association of Disabled Parents in Norfolk, 1996; Grimshaw, 1992; Geirdal, 1989). Physical activities, such as play with young children, walking, and sports, are particularly problematic. While holidays, day trips, and outings may be curtailed because of symptoms or treatment, parents with physical disabilities report restrictions are frequently due to lack of transport, finance, and poor access to facilities (Association of Disabled Parents in Norfolk, 1996). Families deal with these difficulties in different ways: some alter family activities so that the parent is included in as many activities as possible, others find this too burdensome and organise activities without the parent (Blackford, 1995; Grimshaw, 1992; Vess *et al.*, 1988).

There is some evidence that chronic illness may *strain relationships between the parent and child.* In qualitative studies of parents with PD and MS (Rehm and Catanzaro, 1998; Blackford, 1995; Grimshaw, 1992), as well as a quantitative study of mothers with MS (Deatrick *et al.*, 1998), both parents and children reported that the ill parent was irritable, impatient, yelled at children, was less affectionate, or interacted less with their child following diagnosis and/or during periods of symptom exacerbation.

Knowing how best to explain the illness to children has been reported as a concern to parents with a range of conditions. Research involving parents with cancer has found that parents struggle with what to tell children about their diagnosis and how best to explain it (Fitch, 1999; Hymovich, 1993; Vess, 1988). Mothers report finding it particularly difficult to balance their concern that providing information will worry or frighten the child, against wanting the child to feel included, and needing the child's help and cooperation (Fitch, 1999). Attempts to shield children from anxiety provoking information have also been reported by the spouses of parents hospitalized for treatment in critical care units (Titler *et al.*, 1991). Parents with RD feel that talking to children is important so that the child understands the parent's limitations, do not think that they have caused the illness, or worry too much about the parent (Barlow *et al.*, 1999; Allaire, 1988). However, some have difficulty discussing its hereditary nature (Barlow *et al.*, 1999).

Hospital stays can be a source of stress for some parents. Mothers with breast cancer report that, when they are in hospital, discipline is more lax than usual and children tend to test limits with those in charge. As a result it can be difficult to get children to readjust to normal routines when the mother returns home (Vess *et al.*, 1988). Other parents with cancer have reported that children's visits to the hospital were stressful because they were unsure whether or not the child should visit (Hymovich,1993). When children did visit, they sometimes became upset. In addition, parents were distressed by changes in children's general behaviour during and after the period of hospitalisation, such as being irritable, crying, or not continuing to do well in school.

Worries that unemployment brought about by illness will lead to *financial difficulties for the families*, as well associated feelings of loss of self-esteem, have been reported by parents with cancer, RD, and KD (Smith and Soliday, 2001; le Gallez 1993; Geirdal, 1989; Vess *et al.*, 1988).

In addition to these everyday difficulties, parents have a range of *worries about the future.* Research involving those with a cancer, MS, insulin dependent diabetes and a range of life-threatening conditions, has found parents are concerned about whether they will be around to provide care for their children (Fitch, 1999; Smeltzer, 1994; Thorne 1990; Kornblum and Anderson, 1985). Worries that children might develop their parent's condition have been expressed by parents with renal disease (including renal diseases that can not be inherited), MS, and insulin dependent diabetes (Smeltzer, 1994; Kornblum and Anderson, 1985; Friedlander and Viederman,1982).

For women with a chronic illness, *pregnancy* can be an issue for two reasons. First, women report upset at the negative reactions of others, including relatives, friends, specialists in disability, and family doctors (Smeltzer, 1994; Goodman, 1992). Second, the impact of the pregnancy on the illness, and vice-versa, the impact of the illness on pregnancy, can be a worry (Smeltzer, 1994).

Finally, parents' report *negative emotional reactions* to the difficulties they experience. These include feelings of guilt, due to concerns about parenting ability and being a burden to their family (Barlow *et al.*, 1999; Vess *et al.* 1988; Friedlander & Viederman, 1982), depression (Barlow *et al.*, 1999; Grimshaw, 1992), and anger and impatience with children (Barlow *et al.*, 1999; Rehm and Cantazaro, 1998). Further evidence of such emotional reactions is provided by research with children, which is discussed in section 4.3.1 of this review.

Positive effects of the illness on parents

Despite the difficulties encountered, parents have been able to identify positive aspects to being a parent with a chronic illness. Parents with a range of physical disabilities and other chronic illnesses, mothers with RD, and parents with PD, report feeling that they spend more time engaged in shared activities with their children than they would otherwise have done, including talking more to their children than other mothers (Lundwall, 2002; Barlow *et al.*, 1999; Wates, 1997; Grimshaw, 1992; Allaire, 1988). Parents with a range of chronic illness report feeling that they are more affectionate towards their children as a result of their condition (Lundwall, 2002). It has also been suggested by mothers that a beneficial effect of illness is that it forces the family to 'slow down' (Allaire, 1988). Females with PD and MS have suggested that their obligations and desires as mothers help them cope with their condition (Grimshaw, 1992), including fighting against depression, and assisting some in overcoming suicidal ideas (Steck *et al.*, 2000). Mothers with cancer also report a change in priorities, with their family and being involved in their role as a mother becoming more important as a result of their diagnosis (Kayser and Sormanti, 2002).

Factors that influence experiences

The research is beginning to identify factors that moderate experiences. First, a number of studies suggest that difficulties related to childcare are greater when the ill parent is the mother, and children are of pre-school age. For example, in a qualitative survey of

parents with KD, women were frustrated that they had little energy to do things with their family, whereas men were more concerned with the effect on employment (Smith and Soliday, 2001). In a qualitative study of families in which a parent had PD, mothers reported greater strain from younger children, who required additional energy and patience (Grimshaw, 1992). Mothers with breast cancer report that the demands they faced were reduced when children reached school-age because the children helped out with chores (Hilton, 1996; Hilton and Elfert, 1996). Finally, in a survey of parents and grandparents with arthritis, the proportion reporting difficulties with child care tasks varied considerably depending on the child's age and parent/grandparent's sex. Women had greater difficulty than men (Barlow *et al.*, 1999), and had greatest difficulty with children under five years. It seems likely that the greater difficulty experienced by women compared to men is due to having more responsibility for childcare tasks, but it may also relate to the importance they place on their role as parent. In a qualitative study of mothers with cancer, those who saw their ability to care for others as central to their sense of identity had greater difficulty accepting their diminished ability in this area (Kayser and Sormanti, 2002).

Second, the possibility that single parents experience more difficulties than those with partners is alluded to within a number of studies that highlight the important role that partners play in providing support (see section 4.2.2 for further details). Just one group of researchers have assessed the impact of marital status on parental and family functioning in depth, comparing the experiences of 22 single and 101 partnered mothers with early stage breast cancer using standardised instruments (Lewis *et al.*, 1996). Single mothers had a significantly larger number of concerns about the pressures of the illness on their family, their social relationships and their self-image, and a larger proportion had scores indicating risk of clinical depression (36 per cent compared to 17 per cent of those with partners). However, a significantly higher proportion of women in the single parent group had a mastectomy compared to the partnered group (93 versus 62 per cent respectively), and this may explain the differences detected, rather than marital status.

In a second study by this group of researchers, this time involving mothers with a range of chronic illnesses, when assessed using standardised instruments, chronically ill, happily married women shared significantly higher levels of family functioning, compared with chronically ill, unhappily married women and single women. There was also a non-significant trend for single women to experience the greatest level of depressed mood, followed by unhappily married women (Yates *et al.*, 1995). The authors conclude that higher marital *quality*, rather than marital status, facilitates family adjustment within the

context of chronic illness. However, such a trend might be found within *any* family, and further research is needed to investigate whether the quality of the relationship with the spouse/partner moderates the effect of parental chronic illness.

Finally, based on three case studies, Barnes *et al.,* (1998) describe how developmental problems in a child can compound the difficulties experienced by parents. Under these circumstances, parents were very involved in caring for the child with developmental problems and the possibility of diminished ability to carry out this role caused a great deal of anxiety.

4.4.2 Parents' views on the support available to them

Support to parents with a chronic illness may be available from a wide range of sources, both formal (social services, health services, local education authority, schools) and informal (immediate family, extended family, friends, and neighbours). In this section, evidence on the help provided by each of these sources is described to provide an insight into the type of support parents' value and unmet support needs.

Support received from the immediate family

For many years, there has been an interest in the extent to which families deal with chronic illness by redistributing roles and responsibilities. Qualitative studies involving families where a parent has MS, breast cancer, PD, RA and a range of disabilities have highlighted the important role that partners play, stepping in to take over childcare and household responsibilities, ensuring that the ill parent gets the rest they need (Rehm and Catanzaro, 1998; Hilton and Elfert, 1996; Grimshaw, 1992; le Gallez,1993; Goodman,1992), and acting as intermediary within the family, protecting children from contact with an irritable or upset parent (Grimshaw, 1992). However, in some instances, offers of assistance from partners may be turned down for fear the partner will become resentful at having to do too much (Wates, 1997).

The extent to which children take over household responsibilities has been of concern to a number of researchers, and is discussed in some detail in Part two of this review. However, in terms of parents' support needs, the important point is that many parents do not consider this a desirable coping strategy (Wates, 1997; Grimshaw, 1992). As a result in some families domestic tasks are simply not done during periods when the parent is unwell (Blackford, 1995). Nevertheless, where the level of care required by the parent who is ill is very high, or the parent does not have a partner, it may be unavoidable for

children to take over some tasks (Hilton, 1996; Lewis *et al.*, 1996; Hilton and Elfert, 1996; Grimshaw, 1992).

Although the aforementioned research gives the impression of others stepping in to take over the responsibilities of the ill parent, support from families can be limited. In a quantitive study, Green (1986) looked at the changes in household responsibilities during the first year after diagnosis of breast cancer. Prior to diagnosis, the breast cancer patient held more total responsibility than other family or support network members. During diagnosis, others assumed a portion of her workload, but by the time of the second interview (6 months to one year later), all families had returned to their pre-diagnosis pattern. In other words, for most of the time the majority of these women continued with part, if not most, of their household and family responsibilities. As a result, Green suggests newly diagnosed breast cancer patients may experience difficulty recuperating at home.

Furthermore, it is important to note that, even in cases where children take on domestic and caring tasks, parents can maintain key parent responsibilities. In a qualitative study of families dealing with MS, while children did sometimes take on a variety of tasks (child care, meal preparation, running errands, physical care of the parent, laundry and yard maintenance), the parent still helped with homework, was someone the child could talk to about worries, did light housework, took care of bills, planned meals, and kept everyone to schedule (Blackford, 1995). In qualitative research concerned with mothers with SCI, although children acknowledged their mothers had shortcomings in dealing with domestic responsibilities, they felt they were good at being interested in, and supportive of, their activities (Westgren and Levi, 1994).

Support from extended family, friends and neighbours

Qualitative research with families in which a mother has a range of illnesses finds that families are more likely to cope with the situation by making alterations to the way the household is managed, than to turn to people from outside the family for support (Stetz *et al.*, 1986). Nevertheless support from extended family, friends and neighbours is likely to be important, and a number of studies have drawn attention to the complex issues involved in determining whether people are offered and accept help from such sources.

First, useful support is not always available to parents from sources outside the immediate family. Wates (1997) found that some physically disabled parents were isolated, and did not have access to sources of support outside the household, due to factors such as not

being able to get out to work, limited access to places where people meet, and lack of accessible public transport. Parents with cancer, MS and a range of physical disabilities, who have received help from friends and family report that, while useful in many instances, it could also be troublesome as it was often not available at times that were convenient, things were not done to the standards preferred, or the help provided was limited (Wates, 1997; Blackford, 1995; Fitch, 1999).

Second, even when support is available, accepting it is not without its difficulties. Some parents refuse help from family and friends in order not to be seen as a failure or burdensome (Fitch, *et al.*, 1999; Wates, 1997). An important factor in determining whether parents accept help from friends is whether they can return the favour. Otherwise parents fear they may jeopardise the friendship (Allaire, 1988). Given the number of trade-offs involved in accepting help from friends and family it is perhaps not surprising that, where families can afford it, some have chosen to pay for help (Hilton and Elfert, 1996; Hymovich, 1993).

Support from service providers

Given the difficulties with support from family and friends, it seems likely that some parents will need help from service providers. Unfortunately, the evidence regarding service provision is not very positive. In the UK, Wates (1997) explored assistance for disabled parents within the home and found many parents had difficulty obtaining such services. Even where services were available, some were unable to use them because of their location, or the times they were available did not fit with family life. Wates also found that the slow speed at which services were delivered could mean it arrived too late, when the crisis had passed.

When support for disabled parents in the UK was investigated by the Social Services Inspectorate in 2000, it was found that councils were providing a wide range of services (parenting courses, counselling, adult day care, child day care, domiciliary care, equipment, child respite, adult respite, occupational therapy, rehabilitation, and transport), but there was considerable variation in provision between councils, and overall social services were better at responding to practical rather than emotional needs. Those who received services were generally satisfied with them, but there were numerous examples of lack of coordination between services, time delays and limited appreciation of the necessity of services to meet the needs of the whole family. Little information was available to parents on the services provided, the eligibility criteria and how to access them. Access to services was further hindered by adult services often not recognising the

potential impact of being a parent, and children's services not recognising parental disability as a reason for assessing children as 'in need' (Goodinge, 2000). Unfortunately, even if support from a social service department is available, and parents are aware of it, some may have difficulty asking for or accepting it, due to concern about being seen as less credible as a parent and, as a result, losing custody of their children (Goodinge, 2000; Wates, 1997; Thorne 1990).

In a follow up survey of social service departments in England, it was concluded that, although there are still many problem areas, there is growing resolve to support disabled parents as a distinct group of service users (Wates, 2002). While it is reassuring to see that support for disabled parents is slowly being addressed, it remains unclear from this evidence what support is available from social services to parents with a chronic illness, many of whom may not be considered disabled by service providers, or by themselves.

Turning next to support from health professionals, in relation to maternity services in the UK, absence of staff with specialist knowledge about the parent's condition is reported in one study, resulting in information provided about pregnancy, birth and childcare often being absent or contradictory (Thomas, 1999). Mothers with physical disabilities report not being listened to by staff, staff being too busy, or providing insufficient care, which led to a deterioration in the woman's and/or the baby's condition (Goodman, 1992). During labour, women who have had many years of experience in managing their chronic illness found that this was ignored by health staff, and those who had medically complicated pregnancies felt that once the baby was delivered, very little support was offered to them as an individual (Thomas, 1999). For those with physical disabilities, access to buildings, including the labour room and its equipment, are also problem areas (Goodman, 1992).

In terms of health services more generally, a small scale UK survey of disabled parents found that half the respondents had reservations about health professionals' understanding of how disability affected the rest of the family, and some also felt there was no acknowledgement of their obligations to their family (Association of Disabled Parents in Norfolk, 1996). Finally, lack of support from health professionals in explaining the parent's condition to children has been noted in studies involving mothers with breast cancer and parents with PD (Barnes, 2000; Grimshaw, 1992).

As discussed in section 4.2.1, parents can have difficulty getting their children to and from school, and getting involved in school life. Just two studies, involving disabled parents, have explored relationships with Local Education Authorities (LEAs) and/or schools

(Association of Disabled Parents in Norfolk, 1996; Wates, 1997). In one of these studies, most respondents could arrange for other parents, neighbours or child minders to take their children to school for them, but sometimes this system failed, and parents paid for taxis. Very occasionally LEA transport was made available, but this could involve finding a minor reason to designate the child as having 'special needs' (Association of Disabled Parents in Norfolk, 1996). In Wate's study, it was pointed out that, although symptoms could make it difficult to get involved with school life, other barriers were lack of accessible buildings, teachers' lack of understanding about the disability, and events being scheduled for the evening, when parents who were ill had less energy (Wates, 1997).

On a more positive note, while discussing support from health, social services, and education professionals, parents in Wates' (1997) study were able to describe examples of good practice. Based on these examples, Wates concluded that the four main characteristics of good professional-parent interaction are: providing encouragement, supporting a parent's way of doing things, helping to find solutions to practical challenges, and opening doors to resources.

What support do parents want from service providers?

Few researchers have asked parents directly about their support needs, and where evidence does exist it is largely about the needs of disabled parents. For example, in an American study of mothers with SCI recruited through rehabilitation centres, the majority of women reported a desire for more community funding for adaptive equipment, access to housing, schools, transportation, and recreational programs (Alexander *et al.*, 2001). In the UK, when disabled mothers with young children were asked about the help they wanted, suggestions fell into the following categories: more help and support at home; more advice and information; better trained and informed medical staff; more caring and understanding medical staff; better facilities outside the home, and more understanding from employers and the general public (Goodman, 1992). In a small scale study of American parents with a range of chronic illness who responded to a questionnaire posted on the internet, half wanted counselling for their family, but had little interest in support groups (Lundwall, 2002).

In some qualitative studies suggestions have emerged from the data. In two studies carried out in the UK, one involving mothers with breast cancer (Barnes, 2000), the other parents with PD (Grimshaw, 1992), a need for assistance in explaining the condition to children was reported. In Grimshaw's study a few also wanted contact with other families in the same situation. In a survey of Norwegian mothers with RD, who had children aged

six years or younger, it was suggested that the difficulties mothers experience could be reduced if their family was given good information on the condition and its treatment, if partners and the family were actively involved in planning the care of the baby, if a network of mothers was set up, and people were helped with reducing their own expectations regarding mothering (Ostensen and Rugelsjoen, 1992).

Finally, in a report on support groups set up for young mothers with arthritis in Norway, participants wanted advice on practical matters, such as lifting children, while others wanted to discuss sensitive subjects they did not usually discuss at home (Geirdal, 1989).

4.2.3 Summary of findings

Given the limitations of the current research, any conclusions about the impact of chronic illness on parents must be tentative. Overall, the findings suggest that being a parent may be a source of stress for many patients with a chronic illness, though it is unclear what proportion of parents experience difficulties. Sources of stress include: dealing with parental responsibilities, exacerbation of symptoms due to childcare and domestic responsibilities, restrictions to family social activities, strain in the relationship between parent and child, the impact of hospital stays on children, talking to children about the illness, dealing with pregnancy, and worries about the future. As a result, parents report feelings of guilt, anxiety, depression, and anger. Nevertheless, there also appear to be some positive aspects to the experience, with some parents reporting that the role motivated them to cope with their illness, and that there were benefits for the family in that they gave parenting more priority, spent more time together, the parent was more affectionate, and they had a slower pace of life.

The few studies involving mothers and fathers suggest there may be gender differences in the experience of parental chronic illness. Despite changes in attitudes, in general mothers take the major responsibility for childcare (Mill, 2001). It is therefore not surprising that mothers appear to be more concerned about parenting difficulties.

Research into the support parents receive from family, friends, and extended family, indicates that the immediate family, particularly partners, are an important resource for parents, helping them to manage difficulties with parenting and household tasks. However, partners are not always available, and even if extended family and friends provide support, it can sometimes be difficult for parents to accept help from these sources. Evidence from both qualitative and quantitative research points to the possibility

that single parents are more likely to experience difficulties, and may need children to take on more responsibility within the home than they would wish.

From research on support received and supported needed, it seems practical help within the home is needed by some parents, but it will be of little benefit unless it fits in with the family's routine. In relation to education services, assistance is needed in transporting children to and from school, and ways of enabling parents to get involved in school life, both by making the school more accessible, and by finding ways of keeping parents in contact with the school even though they are unable to visit in person.

Within health services, it is apparent that maternity services tailored to the needs of chronically ill mothers are needed. This requires both that staff are knowledgeable about the mother's illness, and that they respect the mother's own views as to how to manage the pregnancy and labour. Amongst generic staff, there is a need for awareness of the chronically ill parent's family responsibilities, greater assistance in explaining the parent's illness to children, and more information for other family members.

Other needs, that could be addressed by any one of the service providers, including the voluntary sector, are contact with other families in a similar situation, awareness raising about chronic illness amongst employers and the general public, and advice on how to cope both practically and emotionally. In addition, professionals in general need to take a more positive approach to parents with an illness or disability, encouraging and enabling them to cope, which in turn may provide reassurance that children are not perceived as being at risk.

Finally, while the findings highlight parents' concerns about whether they are good enough parents, and a need for practical and emotional support in order to reduce stress, conclusions about how well people with chronic illnesses parent should not be drawn from this work. The limited research comparing parents with an illness or disability with healthy control groups either finds no difference in performance, or is too flawed to draw any firm conclusions. Furthermore, the most frequently reported concern by parents is their ability to deal with childcare tasks, yet this is unlikely to be a critical factor in determining children's well-being. In research on parenting in general, it is dimensions of the parent-child *relationship* (warmth/support, hostility/rejection, and monitoring and controlling of children's behaviour) that have been most consistently associated with children's psycho-social adjustment (O'Connor, 2002). As pointed out by Geirdal (1989), an important part of offering support to parents with a chronic illness may be helping them to recognise that

the gap between parental performance and the ideals of parenting is considerable in *all* families, and that mothers in particular must learn to permit themselves failure in attaining *'the impossible dream'*.

4.3 Part Two: Research On Children

Literature on the impact of parental chronic illness on children began to emerge in the 1960s, with studies aimed at understanding the origins of psychiatric problems in children suggesting that parental physical illness might be a factor (for example, Rutter, 1966; Ekdahl *et al.*, 1962). By the 1980's there was a growing body of literature on the issue, but much of it was speculative, based on opinion, theoretical orientation, and professional experience, rather than empirical evidence (Buck and Hohmann, 1983). Furthermore, the research evidence was so methodologically flawed that many researchers have chosen not to include it in review papers (Kahle and Jones, 1999; Korneluk and Lee, 1998; Worsham *et al.*, 1997). Over the past twenty years efforts have been made to improve the quality of the research. Today the field has been dominated by quantitative studies, focussing primarily on cancer (See Appendix 3 for list of studies). Typically, researchers begin by assessing children using standardised measures of emotional and behavioural difficulties, before exploring factors that influence outcomes. However, in recent years there has been unease with this type of research since it involves searching for problems in children, without considering well-being and competence (Blackford, 1999; Kahle and Jones, 1999; Korneluk and Lee, 1998).

Although the research is dominated by quantitative research, qualitative studies have also been carried out (See Appendix 4 for further details). These provide a more general overview of the effects of parental illness or disability on children, and an insight, from either the child or the parent's perspective, into why children respond to parental illness in the way they do. In this review, quantitative and qualitative studies are examined together to provide an overall picture of the evidence. The section begins with research on the impact of parental illness on children, before turning to evidence on the support they receive and support they feel they need.

4.3.1 What impact does parental illness have on children ?

The research on parental chronic illness describes a wide range of effects on children, some of which are viewed as positive by parents and children, others are clearly negative

(see Table 4 for an overview). In addition, there has been considerable interest in how children's responsibility within the home is affected. Children's responsibility cannot be categorised as either positive or negative since, as will be discussed later in this review, research suggests individuals perceive it differently - some as beneficial to the child, others as problematic. In this section, the findings in relation to these three themes are described in turn, beginning with positive effects, before turning to responsibilities within the home, and negative effects. Finally, the small, but growing, body of literature on factors that influence children's psychological well-being is considered.

Table 4: The impact of chronic Illness on children - Themes to emerge from the research literature

Positive effects on children
Child feels closer to their family
More compassionate
Child's ability to cope with adversity is strengthened
More independent than peers
Develop a work ethic at a young age
Mixed effects
Increased responsibility within the home
Difficulties experienced by children
Family's social activities restricted
Reduced social activities with peers
Family conflict
Parental hospitalisation
Coping with parent's emotional reaction
Seeing the parent ill or very fatigued
Worry about parent dying
Worry about developing the parent's illness
Other worries about the future
Financial limitations
Emotional and behavioural difficulties

Positive effects of parental illness on children

Parents' views on the positive implications of parental illness for family life were discussed in Part One of this review, and included more time for shared activities and forcing the family to 'slow down'. Some children also feel parental illness can have a positive effect on families, reporting that their experiences brought them closer to their family (le Gallez, 1993; Nelson *et al.*, 1994; Lewis *et al.*, 1985). In addition to the effect on family life, parents involved in qualitative research have suggested that there may be positive effects on children's development. These include that their children are more compassionate and

sensitive to the needs of others than they might otherwise have been (Lundwall, 2002; Smith and Soliday, 2001; Barlow *et al.*, 1999; Thorne *et al.*,1990; Allaire, 1988; Friedlander and Viederman,1982); that the child's ability to cope with adversity is strengthened through watching the parent face difficulties (Smith and Soliday, 2001; Allaire, 1988); that children are more independent than their peers (Barlow *et al.*, 1999; Rehm and Catanzaro,1998), and develop a work ethic at a young age (Rehm and Catanzaro,1998); or are generally helpful (Lundwall, 2002). Unfortunately, the prevalence of such positive effects, or whether children differ from their peers on any of these dimensions, has not been investigated.

Mixed effects – children's responsibility within the home

It is difficult to know how much children of chronically ill parents get involved in household tasks and caring responsibilities since there is very little research which has investigated this matter, and studies that do exist are often limited by lack of a control group. For example, in a study of disabled parents, six out of 42 parents felt their children helped with household tasks over and above what was considered normal for families with non-disabled parents (Association of Disabled Parents in Norfolk, 1996). However, these chores were often minor and the authors point out that it could be difficult for families to judge what was normal if they were isolated from other parents. Cassino *et al.* (1997) did compare levels of responsibility with that taken on by a control group, finding significantly more mothers with asthma reported that their children were responsible for chores usually performed by their parents than a comparison group. However, as discussed in Part One, the extent to which this sample is representative of parents with asthma is questionable.

A number of qualitative studies suggest that age has a strong influence on involvement, with older children, in the teenage years, much more involved in helping out (Stommel and Kingry, 1991; Vess *et al.*, 1985; Dhooper, 1983). As discussed in Part One, the presence of a partner/spouse within the home may also influence involvement, with research on breast cancer finding that single mothers were particularly dependant on adolescents for assistance (Hilton and Elfert, 1996).

Qualitative research also suggests considerable variability in the way children perceive the tasks they take on, with only a small proportion finding it problematic (Nelson *et al.*, 1994; Craft *et al.*1993), and some welcome the opportunity to help at a time of crisis (Craft *et al.*, 1993), or believe it has brought them closer together as family (le Gallez , 1993).

Parents also hold different views on whether taking on household tasks and caring responsibilities is beneficial or detrimental to children. Some believe such responsibility helps their child develop a work ethic and independence (Rehm and Catanzaro,1998; Friedlander and Viederman,1982). Others express concern that it results in their child becoming independent too quickly (Thorne, 1990).

It is clear from the existing research that children do not passively accept additional responsibilities. In Hilton's research, although single mothers turned to their teenage children for support, teenagers wanted to spend time with peers and this led to arguments about who did what and what were fair task allotments (Hilton and Elfert, 1996). Wates (1997) also found a great deal of variability in children's receptiveness to helping out: while parents provided accounts of adaptability and helpfulness, there were also accounts of non-cooperation.

A few studies provide some indication as to *why* children may react differently to the responsibilities they take on. In a study of mothers with breast cancer, in which adolescents participated in a series of family interviews held during the year after the mother's diagnosis, most adolescents saw themselves as very busy and over-committed at school and work, and tended to resent extra demands at home (Hilton and Elfert, 1996). In Rosenfield's (1983) small scale study of adolescent girls, whose mother had a maestectomy two to three years previously, those who reported that they took over household chores voluntarily had a positive attitude towards such chores, whereas others who had chores imposed reacted negatively to them. The author therefore suggests that voluntarily assuming household chores during an illness might be a positive coping strategy that may subsequently contribute to autonomy and sense of personal growth. In Blackford's (1995) study of children who have a parent with MS, children suggested they were empowered by the work when they felt that load allocated to them was fair. However, even those who generally saw their responsibilities positively, at times felt they were a burden. This happened when the level of responsibility got too great, the parent's fatigue and irritability interfered with the negotiation of the task, and when the help the child provided felt inadequate because the parent's needs were so great.

Difficulties experienced by children

In terms of difficulties for children, it has already been mentioned in Part One of this review that a major concern for parents is that their illness or disability *restricts the family's*

social life. Research with children supports this, but suggests there may be age differences in whether restrictions to family social activities are problematic for children. In a qualitative study involving children whose mothers had breast cancer, Lewis *et al.* (1985) found that, while 10-13 year olds were preoccupied with how much the illness disrupted or changed their lives, adolescents were torn between wanting to spend time with their mother and wanting to do their own thing.

In addition to the family social life, the *child's social life with peers may also be affected.* Parents with a disability report sometimes limiting their children bringing friends home to visit, or that children are reluctant to invite friends home because of their disability (Association of Disabled Parents in Norfolk, 1996). In Nelson *et al 's* (1994) qualitative study of children whose parents had cancer, many recalled giving up sports and hobbies, and spending less time with friends, when the parent became ill. Such findings are given particular significance when it is considered that in a number of studies spending time with friends is described by children as something which helps them cope with the stress of the parent being ill, enabling them to forget about the parent's illness for a time and enjoy themselves (Nelson *et al.*, 1994; Craft *et al.*, 1993; Issel *et al.*, 1990).

A few studies have suggested that a *child's school work and attendance* may be disrupted. In Nelson *et al's* (1994) research on cancer, some children said they arrived late at school or left early because of responsibilities for getting siblings to and from school. In a survey of mothers with asthma, they were more likely than a healthy comparison group to report that their child missed or was late for school because of the parent's health (Cassino *et al.*, 1997). However, as discussed previously (see section 4.2.1), this study is based on a relatively impoverished group of mothers and it would be unwise to generalise the findings beyond this sample.

Parental hospitalisation has been reported as difficult for children for a number of reasons. Parents with cancer have suggested that hospital visits, and dealing with separation from the parent while in hospital, are sources of stress for children (Zahlis and Lewis 1998; Hymovich,1993). Children of parents admitted to a critical care unit have spoken of finding medical equipment frightening, disruption to normal family routine, and feeling lonely, particularly when they had to stay with relatives or friends rather than at home (Craft *et al.*, 1993).

As discussed in Part One, the difficulties parents experience can lead to a range of *negative emotional reactions.* Research with children confirms that they are witness to

these reactions. In a number of qualitative studies concerned with MS, children described parents yelling, crying, being irritable, impatient, and having mood swings (Rehm and Catanzaro, 1998; Blackford, 1995; Kalb, 1996). They have also pointed out that sometimes the well parent may also react in a similar way due to the stress of looking after the parent with MS (Rehm and Catanzaro, 1998). Anxiety, irritability, and depression in the well parent, have also been reported by children who have a parent with cancer (Nelson *et al.*, 1994).

Another closely related, and prominent theme, within research with children is that *of family conflict.* In qualitative research, adolescents whose mothers had breast cancer, and children whose parent had been admitted to a critical care unit, reported increased arguing within the family (Hilton and Elfert, 1996; Craft *et al.,* 1993). Children who have a parent with cancer have also spoken of a deterioration in their relationship with the ill parent (Nelson *et al.*, 1994). In a rare quantitative study on the matter, Peter and Esses (1985) compared the perceptions of young people who have a parent with MS with those in a comparison group, and found that those who had a parent with MS scored higher on family conflict and lower on family cohesion.

Seeing the parent ill, including in severe pain, or attached to medical *equipment,* has been reported as upsetting for children by both parents with cancer and children who have parents with MS (Zahlis and Lewis 1998; Kalb, 1996: Hymovich,1993). Parents with cancer have also suggested children are embarrassed by the ill parent's appearance (Hymovich, 1993).

Worries about the ill parent dying are reported by children in studies of mothers with breast cancer (Zahlis, 1998; Rosenfield, 1983). However, such worries are not confined to families dealing with cancer. Parents with KD and insulin dependent diabetes, have reported being aware that their children worry that they will die (Smith and Soliday 2001; Zahlis and Lewis, 1998; Kornblum and Anderson, 1985).

Worries about the inheriting the parent's condition are a source of stress for children who have a mother with breast cancer (Zahlis Hooper, 2001; Rosenfield, 1983), a parent with RD (Le Gallez, 1993), and parents with a variety of cancers (Vess *et al.* ,1988).

Other less frequently mentioned sources of stress for children are *adapting to, or worrying about, the financial limitations* placed on the family (Zahlis and Hooper, 2001; Blackford, 1995; Kalb, 1996), *worrying about talking to their mother and/or friends about the parent's*

cancer (Hooper Zahlis, 2001; Zahlis and Lewis,1998; Hymovich,1993), and a *range of worries for the future* (uncertainty about what would happen to the parent and how their own lives might change; how the family will manage if the disease progresses, and concern that the mother might change physically or mentally).

Given the aforementioned sources of stress, it is perhaps not surprising that a wide range of *negative emotional and behavioural reactions* in children have been reported. In qualitative studies, parents with cancer, KD, a range of chronic illnesses or disabilities, and those who have had a heart attack, report increased clinging and crying, the child seeming 'sad', 'edgy', or withdrawn, being irritable, misbehaviour, over-eating, sleeping difficulty, complaining of physical ailments, lacking energy or being inactive, and problems with concentration at school and academic achievement (Smith and Soliday, 2001; Zahlis and Lewis 1998; Hilton and Elfert,1996; Hymovich 1993; Dhooper, 1983). Children themselves also report a range of negative emotional reactions in studies of cancer and critical care hospitalisation (Nelson *et al.*, 1994; Craft *et al.*, 1993; Rosenfield, 1983). These include depression and sadness, anxiety, sleep disturbance, weight loss, and psychosomatic symptoms such as headaches, dizziness, and abdominal pain.

There is evidence from qualitative studies that in some cases emotional and behavioural difficulties are time–limited. For example, in Dhooper's (1983) study on parents who have had a heart attack, families reported that three months after the heart attack their children's lives had returned to how it was before the illness, and they were showing no overt anxiety. In Nelson and colleagues' (1994) study on breast cancer, in which children were interviewed 2-6 years after the diagnosis, most children reported that life was back to normal at the time of the interview, and few admitted to long-term worries or anxiety. Daughters of women with breast cancer, who reported difficulties coping with school work, specified that these difficulties were transient, present only during the period when the parent was having a mastectomy (Rosenfield, 1983). However, these studies are based on conditions in which treatment is time-limited and, once complete, family life can potentially return to normal. In many chronic illnesses, including IBD, this is not the case, and it possible that in these situations children's difficulties are not so transient.

A large number of quantitative studies have assessed the level of emotional and behavioural distress in children, whether it differs from that in the general population, and is of sufficient severity to require intervention. In reviews of the literature, it is noted that 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 (Kahle and Jones, 1999; Korneluk and Lee, 1998).

When data are based on children's self-reports, research has found elevated levels of psychological distress, although *most* children do not score in the clinical range (Steele *et al.*, 1997; Compas *et al.*, 1994, 1996; Mikail and von Bayer, 1990). This is different from research based on parents' and clinicians' assessments, where findings are less consistent. Here studies involving parents recently diagnosed with cancer (Howes *et al.*, 1994; Welch *et.al*, 1996), and those with RA (Lee and Gotlib, 1989) and haemophilia (Steele *et al.*, 1997; Kotchick *et al.*, 1996) have found no problems in children's psychosocial adjustment, whereas problems are reported in studies of chronic headache sufferers (Mikail and von Bayer, 1990). It has been suggested that the discrepancies may be due to a child's desire to conceal problems from parents for fear of causing upset (Korneluk and Lee, 1998), though they are also in line with the general literature on how parents and children respond to measures of child adjustment, and may simply reflect that parents are often not aware of the emotional problems their children are experiencing (Seiffge-Krenke and Kollmar, 1998; Achenbach *et al.* 1987). Overall it is concluded that, while children may be distressed by their parent's illness, they are not at risk of psychosocial problems in the clinical range of severity (Kahle and Jones, 1999; Korneluk and Lee, 1998).

Factors that influence children's psychological well-being

A number of studies have attempted to uncover factors that influence the impact of parental illness on children's psychosocial well-being. Some are qualitative, but the majority are quantitative. Unfortunately, it is difficult to draw any firm conclusions from this research as so few studies have been carried out, and where findings across studies are inconsistent, it is difficult to determine why, since the research often involves different conditions, collects data from different sources (parents, teachers, and/or the young person), and uses a variety of measures for assessing the variables of interest. Furthermore, although investigators are concerned with identifying predictors of children's psychological well-being, the majority of the research is based on cross-sectional surveys, so causality cannot be assumed. It should also be noted that some aspects of parental illness reported to be problematic for children (restricted social life, parental hospitalisation), and therefore likely to be mediators of emotional and behavioural difficulties, have yet to be investigated in quantitative studies.

One of the more consistent findings to emerge from the quantitative research to date is that it is not the illness severity as assessed by objective measures that determines the child's adjustment, but *the child's perception of the illness.* This includes perceptions of the seriousness of the illness (Nelson and While, 2002; Compas *et al.* 1996, 1994; Conrad and Hammen,1993), and uncertainty about the illness (ambiguity about symptomatology, diagnosis, treatment, relationship with caregivers, and planning for the future) (Steele *et al.,* 1997b). Evidence is also emerging from quantitative research that the *parent's psychological adjustment to the illness* is a better predictor of children's adjustment than illness severity (Nelson and While, 2002; Steele, *et al.,* 1997a; Jamison and Walker, 1992).

In addition, the *child's psychological and cognitive resources* seem to play a role, with the child's self-esteem a significant predictor of better adjustment in studies of cancer and diabetes and arthritis (Nelson and While, 2000; Conrad and Hammen, 1993). Conrad and Hammen also found that mothers' reports of the child's friendships and higher academic performance also predicted better adjustment. However, as highlighted previously, such findings are based on cross-sectional surveys, and causality cannot be assumed. For example, it is possible that children who are better adjusted have more friendships and are better able to perform academically.

Quantitative research on *the impact of coping* finds that children's use of emotion-focused strategies, particularly avoidant coping strategies, is associated with poorer adjustment (Steele *et al.,* 1997a; Compas *et al.,* 1996; Kotchick *et al.,* 1996), and that avoidant coping, by either the ill or well parent, is also associated with increased parental reports of internalising or externalising problems in the child (Steele, 1997a; Kotchick *et al.*, 1996). However, this research is limited to assessing general coping style, rather than examining how individuals cope with the different types of stressors associated with parental chronic illness (Korneluk and Lee, 1998).

The child's age has been of interest to a number of researchers but it is hard to draw conclusion from the findings since different studies deal with different age groups, and parents and children do not always agree. For example, within qualitative research on PD, parents felt older children (16-24 years) were more vulnerable to stress or social embarrassment. However, young people said as they grew older, and their understanding of the condition increased, they were more accepting of the situation (Grimshaw, 1992). In a study of families dealing with a parent's heart attack, parents felt six to 12 year olds were more adversely affected than pre-schoolers, who were considered too young to

understand the seriousness of the situation, and the presence of the other parent or substitute carer was felt to be sufficient to meet their needs (Dhooper, 1983). Quantitative studies involving parents with cancer, suggest adolescents are at greater risk of developing psychosocial difficulties than younger children (Grant and Compas,1995; Compas *et al.*, 1994; Howes *et al.*, 1994).

The few studies that have looked at the resources available within the family have found associations between the child's adjustment and the quality of the child's relations with the non-ill parent (Lewis *et al.*, 1989; Steele, *et al.*, 1997a). Greater family cohesion and lower conflict were also associated with better child adjustment (Hirsch *et al.*, 1985). No association was found between the child's psychosocial functioning and either social support or income in families in which the mother had breast cancer, diabetes or fibrocystic breast cancer, (Lewis *et al.*, 1989). However, this was a small-scale exploratory study in which parents had high levels of income, education and social networks. Thus lack of variability within the sample may explain the non-significant results.

Only one study has explored the role of *family responsibilities.* Grant and Compas (1995) carryied out a quantitative study on children's psychological adjustment to parental cancer, and found support for their hypothesis that the relationship found between maternal cancer and anxious-depressed symptoms in adolescent girls is due to adolescent girls being faced with increased family responsibilities that are experienced as burdensome or stressful.

Only two studies have examined the role of the *parent's marital relationship* and have produced contradictory findings, which may be explained by differences in the measures used to assess the marriage and the child's adjustment. Lewis *et al.* (1989) found a link between marital satisfaction and child adjustment, as assessed by the peer relations sub-scale of the Family and Peer Relationship Questionnaire, in families where the mother had breast cancer, diabetes or fibrocystic breast disease. Steele *et al.* (1997a) found no link between marital conflict witnessed by the child and child difficulties, as assessed by the Child Behaviour Checklist and the Child Depression Inventory, in families with haemophilia. Another explanation for the discrepancy in findings may be that Lewis and colleagues relied on fathers for data, and it may be that marital dissatisfaction and depression cause parental perceptions of poor psychosocial functioning in children (Kahle and Jones, 1999).

Finally, it has been hypothesised that children are more likely to be distressed if levels of *communication about the illness within the family* are poor and an initial exploratory study by Nelson and colleagues (1994) supported this hypothesis. However, in a larger scale follow up study no relationship was found between poor communication within the family, or lack of knowledge about the illness, and children's adjustment (Nelson and While, 2002).

4.3.2 Support available to children

Evidence on services developed in the UK to support children who have a parent with a chronic illness is notable by its absence. In Canada and the United States a number of psychoeducational interventions have been developed for families in which a parent has cancer, some aimed at the whole families, others solely at the young people (Hoke, 1997; Taylor-Brown *et al.*, 1993; Greening, 1992; Walsh-Burke, 1992). Unfortunately, systematic evaluations of these interventions have not been carried out, and the review of the literature uncovered no evidence of similar interventions in the UK.

In the UK, a small scale exploratory study has been carried out into how children's visits to see a parent in adult intensive care units are managed (Clarke, 2000) – an important issue given that hospital visits are a source of stress to children and parents. It was found that, despite an open visiting policy, children rarely visit adult intensive care units to see their parents. Interviews with nurses suggested that the main reason for this was the wishes of the well parent. However, nurses did not actively encourage children to visit, waiting for the family to raise the issue, and sometimes dissuaded the family from bringing children to visit in order to protect the patient from noise, fatigue and infection, and themselves from the emotional trauma involved in such a visit. When children did visit, nurses tried to cope with it as best they could, without collaborating with other professionals, despite not having training in how to manage such situations. These findings are disappointing when it is considered that a Canadian study found that almost all young people who had visited their parent in a hospital critical care unit said it had been useful, reducing feelings of worry (Craft, 1993). It would be interesting to know more about how children's visiting is managed in situations where the parent's life is not in immediate danger. Unfortunately research on this matter does not appear to have been carried out.

Views on children's support needs

Across studies, parents' views on whether or not children need support of any kind from outside the family are not consistent. For example, in Dhooper's (1983) research with families dealing with heart attack, most parents felt they were able to recognize the feelings and fears of their children and could give them the reassurance they required. However, in a study of breast cancer mothers said that a number of factors prevented them from helping their children as much as they would like, including not knowing what to say or do, feeling too sick and tired, or being wrapped up in their own struggle (Zahlis and Lewis 1998).

A number of studies have looked specifically at children's information needs. Again, parents' views are inconsistent. In Grimshaw's (1992) study of PD, a few parents identified a need for a booklet for children explaining the condition. However, in a study of parents with insulin dependent diabetes (Kornblum and Anderson, 1985) parents felt their children did not need further information about the disease, since they rarely asked questions about the condition. However, lack of questions may not be a very good indicator of need: in research with children who have parents with MS many did not like to discuss the illness with the parent in case it upset them (Rehm and Catanzaro, 1998).

Like parents, young people have mixed views on whether they need more information. Studies of breast cancer and RA report that children want more information (le Gallez, 1993; Rosenfield,1983; Lewis *et al* 1985), particularly on the disease, its treatment and prognosis (Rosenfield,1983; Lewis *et al* 1985). However, in a study about MS, children had no interest in reading available literature, explaining that they tried not to think about the parent's condition (Kalb *et al* 1996). In a study of PD, views were mixed, but where young people had talked to their parents about the condition they acknowledged it had been useful in enabling them to address issues that were worrying them (Grimshaw, 1992).

A few papers comment on whether it might be useful for young people to meet up with others their age in a similar situation (Grimshaw, 1992; Rosenfield, 1983). However, the evidence on which this is based is not substantial, with Rosenfield finding one child in their study wanted to meet someone her own age, and another reporting that she had already done this and found it helpful. In Grimshaw's study (1992) parents thought contact with other children in the same situation might be useful, but young people's attitudes to this suggestion were not generally positive. Kalb *et al.* (1996) found that children who had parents with MS had no interest in attending workshops run for families.

The role of schools in providing support to children who have a mother with breast cancer has been investigated in a qualitative study by researchers in Canada (Chalmers *et al.*, 2000). Young people had different needs depending on how they coped with the condition. For some, school provided an environment in which they could detach themselves from concerns about the mother's illness, and they preferred that staff did not discuss their cancer experience with them. However, others wanted recognition of their special circumstances, and an opportunity to discuss their situation with a teacher or guidance counsellor. Girls generally expressed more interest in having support.

Other suggestions from young people regarding the help they would like include being given more opportunity to be involved in the patient's care and treatment (le Gallez, 1993), and some form of individual counselling (Grimshaw, 1992).

4.3.3 Summary of findings

Overall it seems that parental illness can have both positive and negative consequences for children. In terms of positive effects, qualitative data from both parents and their children suggest benefits for family life. Data from parents points to positive implications for the child him/herself, such as being more compassionate, more independent, and better able to cope with everyday difficulties. Researchers have not examined such variables in quantitative studies, so we do not know how widespread such effects are.

The research also suggests aspects of living with parental illness that are problematic for children (restricted social life, family conflict, parental hospitalisation, the parent's emotional reaction, seeing the parent ill, worries about developing the condition themselves, worries about the parent dying, financial difficulties), and it seems likely that if children experience emotional upset it is linked to such experiences. The significance of taking on responsibilities within the home remains unclear, with the qualitative research suggesting that while for some it may be a source of stress, for others it may be a strategy for coping with the situation. To date, there is evidence to support hypotheses that children's adjustment is not determined by parental illness *per se*, but is better predicted by the child's perception of the illness and the parent's psychological adjustment. Furthermore, the resources the child has for coping with their experiences, including self-esteem, coping style, and possibly the relationship with the well parent, and family cohesion, will influence the extent to which they are affected.

Given the limited body of evidence on children's support needs, it is difficult to come to any firm conclusions about how best to help children, particularly as studies based on children and parents' views produce inconsistent findings. Even within studies, research carried out directly with children about whether they want information about the parent's condition, or someone to talk to about the situation has produced mixed results. It seems likely that there is no one solution that will suit all children, and that needs may vary according to how children cope with the condition. In particular, young people who tend to avoid thinking about the parent's illness may be less receptive to interventions. However, given that the parent's psychological adjustment influences the child's emotional and behavioural well-being, it may be possible to help these children by assisting their parents in coping with their condition. Those who are receptive to receiving help are likely to want information on the parent's condition, someone to talk to about their situation, and possibly an opportunity to meet other young people in a similar situation and recognition of their family circumstances by school staff. They may also benefit from being supported when visiting their parent in hospital, including explanations as to what is happening to the parent and the purpose of medical equipment.

4.4 Implications For Parents With IBD And Their Children

IBD has many features in common with other conditions included in this review: parents experience pain and tiredness, need hospital treatment, and there is a genetic component to the condition, even if the level of risk is small. It therefore seems likely that many of parents' experiences and support needs reported in this review, will be common to families in which a parent has IBD. They may experience difficulties with parenting responsibilities and dealing with pregnancy, feel their symptoms are being exacerbated, experience restricted social activities, feel their relationship with their child is strained, have difficulty dealing with hospitals stays, worry about their child developing the condition, and struggle with explaining their condition to the child. At the same time they may benefit from spending more time with their children, a slower pace of family life, and feel encouraged to cope with IBD.

Given that IBD is a fluctuating condition, it is likely that any reallocation of responsibilities to the other parent of children will be temporary. Furthermore, much of the research reviewed is based on life-threatening or life-limiting conditions. This is not a feature of IBD, so it is anticipated that fears about parents being around to care for their children in the future will not be as prominent amongst families dealing with IBD. In relation to parents' support needs, it is expected that these will be directly related to the

aforementioned difficulties, but that the extent to which they want help from service providers will depend on how much support is available to them within their family and social network.

In terms of children, it seems that even if the parents experience the aforementioned difficulties, it is unlikely that children will experience emotional and behavioural problems severe enough to warrant clinical intervention. However, they may be upset by aspects of their parent's condition (seeing the parent ill, hospital treatment), any effects on family life (social restrictions, conflict), or on the parent's emotional state. *Some* may want information on IBD, a person to talk to about the parent's illness, an opportunity to meet peers in similar circumstances, support from school staff, and benefit from being supported in visiting their parent in hospital.

Part III

Phase One of the Research

CHAPTER 5

Study 1 - Research Design and Methods

5.1 Introduction

This chapter describes the research design and methods of the first study carried out as part of this thesis – the qualitative research with parents with IBD. It covers the aims and objectives of the study, research sites, recruitment process, methods of data collection, ethical considerations, and method of data analysis. As explained in Chapter 1, this project was funded by NACC. This meant that, unlike the later elements of the research, which were funded by a PhD studentship, there were resources for two researchers – myself and Professor Patricia Sloper, to be involved in data collection and analysis.

5.2 Aims And Objectives

The aim was to find out about the experiences of parents who have IBD. The objectives were to describe parents' views, both positive and negative, on:

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

5.3 Research Sites

Two research sites, based in two NHS health trusts in the North of England, were involved in the research. 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. 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 research. Approvals for the study were secured from the local NHS research ethics committees in both sites.

5.4 The Recruitment Process

Given that Study 1 was qualitative, and the aim to understand the experiences of parents with IBD, rather than to try to represent statistically what is happening in the wider population, a 'purposive sampling' strategy was adopted. Here people who have the experiences relevant to the research are actively sought out (Robson, 1998).

The criteria for inclusion in the study were that the person be a parent (mother or father) of a child aged 16 years or younger, and had been diagnosed as having IBD for at least one year. 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 as to the most effective way of contacting potential participants, a different approach to recruitment was taken in the two sites.

In Site A, a number of strategies were used to recruit participants. First, consultants and junior medical staff gave information packs to all patients likely to have children who attended outpatient clinics during a six week period. I also attended the clinic and was introduced to any patient interested in taking part in the research. Second, in a few instances where a consultant knew that a patient had children, but was not due to attend the clinic during the six week period, the consultant wrote to him/her in person about the study. Finally, the local NACC support group posted out information leaflets to all members thought to have children.

In Site B, the gastroenterology clinic had a database that included the diagnosis, age and contact address of all patients attending their clinic. This database enabled the nutrition nurse at the clinic to post out information packs to all patients with IBD who, based on their age, *might* have children. A total of 40 information packs were sent out, accompanied by a covering letter from one of the consultants at the clinic (see Appendix 5). In this site, no attempt was made to contact people through the local NACC support group since the nutrition nurse, who was in regular contact with the group, advised that all 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 pack given to potential participants included an information leaflet explaining the research and inviting people to take part, a response form and a pre-paid envelope (see Appendix 6). When a potential participant returned a response form

indicating interest in the research, I contacted the person to discuss the study. After checking the parent met the inclusion criteria, s/he was invited to attend a focus group meeting.

5.5 Methods Of Data Collection

It was decided that focus groups would be used to gather information from parents 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), and might be useful in developing recommendations about support for families.

To make attending a focus groups as convenient as possible for parents, meeting were held in the towns where patients attended outpatient clinics. This was near to home for most participants. Neutral venues, away from hospital clinics, were used for all focus groups. 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. Thirteen parents attended one of four focus group meetings (three in Site A, one in Site B). The main reasons given for not being able to attend were family commitments and difficulties in leaving home because of poor health. 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. In order to ensure the views of parents unable to attend groups were included in the study, interviews were offered at home. A further 11 parents opted to be interviewed at home. In two instances a partner was present during the interview.

5.5.1 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 (see Appendix 7 for the topic guide).

During the focus groups, Professor Sloper and I 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 were carried out by a single researcher, and varied in length, lasting between one to three hours. Professor Sloper and I took responsibility for half the interviews each.

Before beginning data collection, all participants completed a consent form (see Appendix 8). They were also were asked to complete a short questionnaire providing the researchers with some background information on their family circumstances and health (see Appendix 9). Once this was complete, the focus group or interview could begin.

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;
- Talking to children about IBD;
- 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.

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 10). At different points during the course of the focus group or interview, they were asked to make a note on the time line of how IBD affected them as parent, and the effects they had noticed in their children. 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.

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 – the Short Inflammatory Bowel Disease Questionnaire

(SIBDQ) (Irvine *et al.*, 1996) and return it to the research team in a pre-paid envelope. 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 SIBDQ is scored on a seven point scale, with 1 indicating poor health and 7 being optimum health. Further details on the validity, reliability and responsiveness of the SIBDQ to changes in disease activity are given in Chapter 9.

5.6 Ethical Considerations

> *Looking at the painful feelings which parents and children have to bear if a parent becomes ill or disabled is disturbing. It is disturbing for professionals who have to struggle between seeing their patient and client as someone in need of care while simultaneously being someone who has to provide care for their children. Raising disturbing issues with an ill or vulnerable patient is not to be undertaken lightly. Even if the patient is well at the time, raising questions about the children may give serious offence.* (Segal and Simkins, 1996: 3)

This extract is taken from a book written by counsellors for professionals involved in supporting families in which a parent has MS. However, researchers working in the field of parental illness face similar issues. A number of steps were taken to minimise the risk of upsetting participants and to ensure we were clear as to how to respond if difficulties arose. First, efforts were made to ensure that participants understood what taking part in the study involved. As discussed previously, potential participants were sent an information pack about the research. This outlined the topics that would be discussed during the focus groups and interviews. In addition, I also telephoned participants in order to talk to them on an individual basis about the nature of the study prior to them agreeing to take part. All were reassured that they were under no obligation to participate and their decision would make no difference to the services they received.

Secondly, focus groups and interviews were designed to create an environment in which participants felt comfortable talking about personal experiences. Focus groups began with a discussion of the ground rules for the meeting, including the importance of discussions remaining confidential to the group, that everyone should have an opportunity to talk about their different experiences, and that people were free to come and go from the meeting as they wished. Having two researchers present during the meeting meant that one could focus on facilitating discussion, while the other was free to assist should

anyone become upset. Prior to interviews, participants were told that tape recording of the discussion was optional, that they could stop the interview at any point, and the procedures used to maintain confidentiality were explained.

To ensure that interviews and focus groups did not end with people dwelling on upsetting issues, topics became less sensitive as data collection progressed, ending with the drawing up of recommendations about service provision. Time was also spent discussing what would happen next in relation to the research, and giving people an opportunity to comment on what it had been like to take part. Professor Sloper and I agreed in advance of data collection that, if a participant became upset, we would stop the interview, check whether the person wanted to proceed with the discussion, and offer to put them in touch with organisations who could provide support.

5.7 Data 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 for this purpose (Ritchie and Spencer, 1994). Framework analysis involves familiarisation with the data through reading transcripts; identifying an initial thematic framework (drawn from a priori issues in the topic guide and emergent themes raised by respondents); indexing the framework against the transcripts; and systematically transferring the data to charts. Each chart forms a matrix for displaying data on a particular theme, with each respondent allocated a row and sub-themes organised in columns. Charts are then examined for patterns and associations.

In this study, in order to increase reliability, both Professor Sloper and I 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 work of charting was split evenly between the two of us. Professor Sloper took responsibility for the interviews, while I took responsibility for the focus groups. After charting each transcript, we checked the written materials (lists and time lines) produced by the participants. Any new data were added to the charts.

Professor Sloper also added any new sub-themes to emerge from interviews 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 is 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. On 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. At this point, I took over responsibility for data analysis, examining the charts for patterns and associations, and writing a summary of the findings. The following chapter reports the results that emerged from this analysis.

CHAPTER 6

An Insight Into Parents' Experiences

6.1 Introduction

This chapter reports on the results of Study 1 – the qualitative research with parents. Data from questionnaires were used to provide a description of the health and family circumstances of participants in the study, and are reported first. Next the findings from the qualitative research are presented. Since findings from this research, influenced the design of the qualitative investigation of children's experiences, as well as phase two of the research– the survey of parents and children, the chapter ends with a summary of the findings, including the strengths and limitations of the study.

6.2 Response Rate

A total of 24 parents, representing different families, took part in the study: 16 from site A and eight from Site B. The response to the various recruitment strategies is given in Table 5.

Table 5: Study 1 - 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

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. It is unclear why there was

a difference in response rate between the two sites. It is possible that the opportunity in Site A to meet with a researcher while attending an outpatient appointment encouraged parents to participate. Another factor is that, due to delays in ethics committee approval, letters were sent to parents in Site B during the summer holiday period.

6.3 Characteristics Of Participants

Nineteen mothers and five fathers took part in study. Parents were aged between 26 and 54 years of age, with a median age of 40 years. Half the sample were members of NACC.

Participants had been diagnosed as having IBD for between one and 36 years (median of 12.5 years). The number of years participants had been experiencing symptoms of IBD was slightly longer, varying between two and 36 years (median of 13 years). A breakdown of the sample by diagnosis is given in Table 6. Fourteen parents had undergone surgery because of their IBD and, at the time of the study, seven had an ileostomy.

Table 6: Study 1 - Diagnosis and SIBDQ scores

Diagnosis	Number of participants	Median SIBDQ score
CD	14	5.0
UC	8	5.4
CD and UC	1	6.2
Proctitis	1	2.5

Twenty of the 24 participants completed and returned the SIBDQ. The median SIBDQ score was 5.0 (1= poor quality of life, 7 = optimum health). The median scores by IBD diagnosis are given in Table 6. These scores fall within the range and follow the general trend reported in other clinical samples, with patients with CD scoring slightly lower on quality of life than those with UC (Irvine *et al.*, 1996). The median SIBDQ scores for those with an ileostomy were slightly higher than for those without (median SIBDQ with ileostomy = 5.7, without = 4.9).

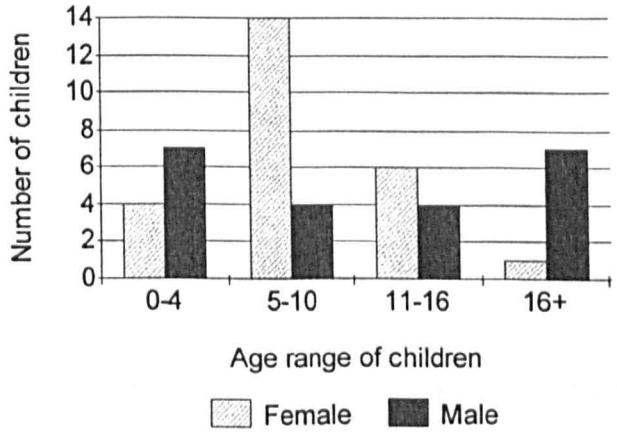
It is worth noting that two of the participants who did *not* complete the SIBDQ had an ileostomy, and another was a parent who felt her condition was very mild. Therefore, it

may be that the participants' quality of life is slightly better than suggested by the mean SIBDQ score for the sample.

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. Parents had between one and four children each (median 2.0). The age range of children varied between under one year and 22 years, with a median age of 8 years. The age and sex distribution of these children is shown in Figure 2.

In relation to employment, eight participants were not working, nine were working part-time, and seven were working full-time.

Figure 2: Study 1 - Age and sex distribution of children



6.4 The Findings

In addition to the topics covered in the focus group and interview topic guides (see Chapter 5, section 5.5.1), evidence emerged on the support parents had received from service providers. Findings in relation to each of these themes follows.

6.4.1 The impact of IBD on parents

Overall parents reported more negative than positive effects. Difficulties seemed to be influenced by three factors related to the Illness – symptoms of IBD, medication, and hospital treatment. Since having an ileostomy was reported to reduce symptoms such as

incontinence, diarrhoea, pain and tiredness, as well as the need for hospital and steroid treatment, it also appeared to reduce the negative effects experienced by parents.

Difficulties also seemed to be greater when children were young, since they needed greater care and attention, and when the mother, as opposed to the father, was ill. Differences between mothers and fathers reflected the extent to which participants were involved in practical parenting tasks. 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 due to ill health when their child was in nursery or primary school, and taking a greater responsibility for caring for their children during this time. Under these circumstances, fathers also reported a few of the difficulties experienced by mothers.

The nature of the difficulties experienced by parents are described below. This is followed by the positive effects.

Difficulties experienced by parents

Incontinence and diarrhoea were major issues 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.*

In relation to their role as parent, these symptoms meant it was a struggle for mothers to care for babies and pre-school children. They spoke of having to feed babies whilst sitting on the toilet and being unable to leave the bathroom to attend to babies who were crying. Going shopping could be difficult, with some saying they had on occasion left their child with strangers in order to get to a toilet urgently.

> *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. ...

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. Some could not use public transport because of lack of toilet facilities, or car journeys for any length of time were problematic. As a result family holidays, day trips and other social activities were limited to some extent.

When children reached primary school, a major problem was getting to and from school and attending school events. Some parents were reluctant to leave their house because of embarrassment about their condition. Consequently, their children could only socialise with other children in their own home. In secondary school, children were more independent, but parents still faced difficulties attending school events. Some reported that even when they were symptom free, fear of incontinence was enough to disrupt everyday life.

In addition to incontinence and diarrhoea, IBD caused pain and tiredness, and there were a number of overlaps in how symptoms affected parents. Pain and tiredness were also reported to limit the family's social life and the parent's ability to spend time with, look after, play, and deal with the behaviour of children. In addition, these symptoms could affect a parent's ability to be physically 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.

Some parents reported that these symptoms also reduced their tolerance, making them irritable and short tempered. On a more practical note, a couple of parents mentioned not having the energy for domestic activities such as cooking. A few parents who experienced nausea as a result of IBD spoke of the difficulty they had in preparing food for their children. 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.

Parents experiencing the aforementioned symptoms were often taking medication, which could further exacerbate difficulties. For example, some medication could make parents feel more tired. A few parents reported adverse reactions to steroids, causing severe mood swings. This was said to be very problematic since it meant difficulties in family relationships at a time when the parent needed family support. Medication was also problematic during pregnancy, since mothers worried about the side effects on the baby.

When in hospital for treatment, parents were concerned about children seeing them unwell or attached to machinery and tubes. As a result, some limited their children's visits, yet parents also found it upsetting to have to spend time apart from children. Most had someone at home who could care for their children while they were in hospital. However, in two cases where such support was not available, social services were contacted, and it was suggested that children be placed into care. Parents had found this very distressing. Returning home after hospitalisation was also problematic, since it was difficult to care for children when not fully recovered from treatment or surgery. 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.

These difficulties led to feelings of worry and guilt, and a number of mothers spoke of periods of depression. In addition, some parents worried about whether they would live long enough to see children grow up and whether the condition was hereditary. Two had children who had frequent bouts of diarrhoea, and they were uncertain about how to respond, and unsure as to whether their child was genuinely ill or simply copying them. 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.

Positive consequences for parents

Despite these difficulties, parents also noted some positive effects. The main one was developing a closer relationship with their children. As one explained:

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

Two 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.

Other positive effects were that IBD was said to have improved parenting by: making people more aware of the child's needs and loving; being alert to the symptoms of IBD, should their child develop the condition; and being relaxed about health matters, aside from symptoms associated with IBD. Even those who experienced many difficulties were keen to point out the positive aspects of being a parent. For example, one mother who experienced many 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.

6.4.2 Effects on children

Most parents reported a mixture of positive and negative effects on their children; a few had not seen any effects. Children in the same family were also reported to vary in their reactions. Parents reflected on the extent to which their children were affected, and suggested differences between children might be due to the child's temperament, with some children more prone to worrying. In addition, differences were attributed to the severity of the parent's condition, and the extent to which a child spent time with other relatives, which was seen as reducing the impact of the condition.

There was no clear picture as to the influence of the child's age. Most parents 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.

Some parents felt the effects of IBD on children were likely to be greater when it is the mother who is ill 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.

Further details on the nature of the positive and negative effects follow below.

Positive effects on children

The most frequently mentioned positive effect on children was showing more care and consideration, both towards the ill parent and to people more generally. For instance:

> *It's 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.*

Support to parents 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.

Others effects were children being more independent and developing closer relationships within the family, including the ill parent and other family members involved with child care, than they might otherwise have done.

Negative effects on children

The most common negative effect was restriction on children's 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. As one parent explained:

> *Some days you're in that much pain, and you're going to the toilet that frequently, you can't get out the bathroom door let alone to the front door and you hear 'I want to go to the park, I want to go swimming, why can't we go here, I want to go there.'*

Others effects were: not having a parent with sufficient energy to play with them; missing out on parents attending special events; the confusion for young children of having a parent with incontinence when they were being taught not to have 'accidents'; the embarrassment for children of having 'smelly' parents, making it uncomfortable for them to have friends in the house; having to look for public toilets on the parent's behalf; babies picking up on the mother's stress; and parents separating when this was attributed to a partner's inability to deal with IBD.

The negative reaction parents noticed most often in their children was anxiety or worry about the parent being ill or going into hospital. 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.

Anxiety and worry manifested itself in crying, the child withdrawing, developing headaches, and checking up on the parent when ill, including not wanting to get involved in social activities that involved staying away from home in case the parent became ill.

Mild misbehaviour, 'playing up', or 'attention seeking', when the parent was ill, in hospital, or on return from hospital, was also reported. A number said their children reacted with anger or frustration to the restrictions imposed by the illness. One mother was able to describe the process she felt led to her daughter's anxiety and difficult behaviour:

> *If I'm not well then he [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 she would be directly proportionally anxious and stroppy and attention seeking and just generally difficult, which makes the whole thing so much more difficult.*

Others felt that their children were embarrassed by their condition.

Overall it seemed that all these reactions were in response to specific incidents and fairly transient in nature.

6.4. Coping with difficulties

Parents used a variety of strategies to deal with the effects of IBD on themselves and their children. The most common strategy was turning to partners and members of the extended family for emotional and practical support. These people were also acknowledged as a source of support for children. One parent reflecting on her initial attempts to manage by herself said:

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

The extent to which parents drew on partners and family was of course limited by availability. Three of the parents 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. A few other parents reported unsupportive responses from partners, including anger and resentment at 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, and organise child care when they needed to go into hospital.

Very few turned to friends or neighbours for help. For some, this was because they did not tell people outside the family about their condition. Others did not want to impose on people. Some mothers were isolated because they declined offers to meet up with other mothers for fear of being incontinent.

Although parents turned to others for support, they were also actively involved themselves in preventing problems from arising. Parents spoke of making efforts to control symptoms

by taking medication at the first sign of a flare up, keeping fit or having an ileostomy. All those 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:

> *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.*

However, parents 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.

Therefore, despite their efforts, some parents explained that often they had little choice but to get on with caring for their children whilst experiencing pain, tiredness and diarrhoea:

> *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.*

A number of parents had decided to have just one child, or had left a substantial gap between children, so that they did not have to care for more than one very young child.

Others alleviated stress on themselves and the family by organising separate holidays, or days out for children on their own.

Aside from more general strategies to reduce the number of difficulties encountered, parents also reported practical strategies for dealing with difficulties that arose regularly, such as incontinence, getting children to and from school, and children's anxiety. These are listed in Table 7.

Table 7: Study 1 - Practical strategies used to deal with parenting difficulties

Coping with incontinence ▪ 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
Coping with difficulties getting children to school ▪ 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
Coping with child's anxiety ▪ 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 ▪ 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

It was also apparent that some passive strategies were adopted. The earlier description of the impact that IBD was having on parents indicated that many were avoiding a range of situations where there was the potential for suffering embarrassment (shopping trips, days out with the family or other parents, school events, and travel of any distance). In addition, avoidance of thinking about difficulties was mentioned by a couple of parents, including the following vivid description by one parent:

> *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.

Finally, parents tried to think positively about their situation and used jokes about the condition to diffuse tension in the family, though they were careful to explain that such jokes were only funny amongst family members:

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

It is worth acknowledging that having children helped some parents to cope with IBD. Children helped out and comforted parents when unwell, and encouraged them to do things they found difficult to manage. Access to toilets was easier with a young child, and parents were able to blame embarrassing smells on babies. However, children were not carers for their parents, with only one parent mentioning children taking on domestic responsibilities to any extent.

6.4.4 Talking to children about IBD

Given the speculation in the literature about the usefulness of talking to children about the parent's illness, participants were specifically asked about this matter. Parents varied in the extent to which they talked to their children about the condition. Some restricted information because they did not want to worry their children, or felt their children were too young to understand. Others were very open about their condition. Again, this decision was made to prevent children from worrying. However, it was clear that the extent to which parents talked to children was not simply related to their views as to whether it was appropriate and/or would be helpful, but also related to how much the children wanted to know. A number of parents explained that they responded to cues from the child that s/he wanted information, and even those who tended to limit information answered children's questions.

In general, those who had given children information reported that it had been helpful since their children were more understanding. There was an exception - one parent said that if anything, it had increased her daughter's frustration and anger because she realised the condition was not going to go away. All parents agreed that it was important to explain things at a level which the child understood. For many parents of younger

children this meant that they never mentioned the terms 'ulcerative colitis' or 'Crohn's disease', but instead talked about having a 'poorly tummy'. Parents struggled with explaining many aspects of IBD to young children. For example, ileostomies, why they were too tired to do things, why they need to use toilets, 'drip feeds', and equipment in hospital.

6.4.5 Support from services

In terms of the support parents received from services, the response of health professionals was reported to be variable. Some members of the gastroenterology team clearly took a holistic approach, helping them to prepare for important family events; taking family circumstances into account when arranging treatment or altering medication; supporting mothers before and after the birth of a child; and putting patients in touch with other parents who had an ileostomy. 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.*

However, other professionals did not offer such assistance and this seemed to depend largely on their individual personalities and interests.

Parents reported a few instances of good practice by generic health care staff, such as a midwife who offered support to a mother who was depressed, and a health visitor who organised for a mother to receive help with childcare from a student at a local college. However, once again staff's responses were variable, and there was widespread concern about the lack of knowledge about IBD amongst generic health staff, including general nurses, health visitors and GPs. This had led to upsetting experiences, such as difficulties obtaining access to toilets when in hospital, staff being unsympathetic, and GPs refusing to make home visits.

A few parents had told staff at their children's schools about their condition and had found this very helpful. Staff had provided access to school toilets, organised lifts to take the child to and from school when the parent was too ill to do so, and understood that the child might sometimes arrive late. As one parent commented:

> *It's amazing how helpful it is to talk to school.*

Only a couple of parents in this study had sought help from social services and the local education authority, and those who had were refused assistance. Within the retail sector, lack of knowledge amongst shop assistants meant that it was difficult to get speedy access to toilets.

A number of parents had found NACC useful in providing a leaflet about pregnancy; providing a newsletter, since it was comforting to know there were other families going through the same experience; and in putting them in touch with someone they could talk to on a one-to-one basis. However, it was recommended that local support groups develop a younger membership and a more attractive, welcoming and fun image to encourage families to get involved with such groups.

6.4.6 Messages for service providers

Participants had very clear ideas on the support that would be useful to parents with IBD and their children. They spoke of the need for practical assistance, information for the parent with IBD, support for the parent in coping with the condition, support for other family members, and awareness-raising about IBD. Full details of suggestions are given in Table 8.

Table 8: Study 1 - Support needed by parents with IBD

Practical assistance

- A crisis support service for parents when ill. This should be targeted at single parents, those without family living nearby, and/or those with young children. It should provide help with transport to and from school, shopping, housework, cooking, and child care when a parent is hospitalised.
- Help contacting family members in times of medical emergency.
- Services to enable parents to receive bowel rest and tube feeding at home.
- Somewhere for parents to convalesce away from family.
- Better access to social and housing services.
- A system for reducing prescription costs
- Access to disabled parking to make it easier to get to toilets quickly.
- Homes to be adapted so that families have access to more than one toilet .
- Information for the parent with IBD
- Information on the effects of IBD on pregnancy and family life, ileostomies, and what to expect on leaving hospital after surgery.
- Information from health staff about the condition to be delivered in a less clinical, more sympathetic manner.

Support for the parent with IBD in coping with the condition

- Gastroenterology services to take account of a family's situation when arranging treatment.
- Advice on taking control of the condition, stress management, and how to deal with sex.
- Advice on what to tell children about IBD.
- Someone for the parent with IBD to talk to about his or her situation.
- Support for parents after the birth of a child.

Support for other family members in coping with IBD

- Opportunities to meet other families in which a parent has IBD.
- Support for partners in coming to terms with the condition, in the form of counselling, written information, and support groups.
- A book written for children which explains IBD.

Awareness-raising about IBD

This should be targeted at:

- Generic health staff, retail companies, teachers and school pupils.

6.5 Summary of findings and implications for future research

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 an 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 and support needs without researchers presupposing what these might be.

However, there are limitations to the conclusions that 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. The size of the sample is acceptable for qualitative research, and as stated previously, the data reached 'saturation point', but there were a number of characteristics of this sample that 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 than many with IBD. Three of the five fathers had an ileostomy and only two of the fathers were employed. In a survey of NACC members, 60.8 per cent of men were employed and unemployment was associated with severe disease (Walters, 2000).

Overall, the findings suggest IBD has the *potential* to create difficulties for parents, both in carrying out their parenting tasks and emotionally, though there may also be positive effects for families, specifically the opportunity for the parent and child to develop a closer relationship through spending more time together and sharing the experience of the illness. The extent to which parents experience difficulties seemed to be related to:

- The severity of their condition;
- The level of inpatient treatment experienced;
- The parent's anxiety about their symptoms;
- Whether the ill parent is the mother or a father;
- The age of the child;
- The level of social support they receive.

The findings also suggest the children of parents with IBD are more likely to be caring towards others, independent, and have close relationships with family members, compared to their peers. However, they also experienced a range of difficulties in their everyday life (social restrictions, parent unavailable to play with child or to attend school events, embarrassment, a 'stressed' parent, and parental separation), and may develop

mild anxiety and behaviour problems. According to parents there were three major determinants of children's emotional and behavioural problems:

- The extent to which the child saw the parent ill;
- Parental hospitalisation;
- Restrictions to social activities.

They also hypothesised that children might have greater difficulty when it is the mother, rather than the father, who is ill.

Although parents report a wide range of support needs, these appear to be largely unmet by service providers: health services focus on treatment of the condition; few parents are in contact with agencies that could support parents; and those that have sought assistance from social services and local education authorities were refused assistance. In addition, parents tend not to discuss their situation with others, preferring instead to 'keep it within the family', so service providers may be unaware they need help.

As outlined in the introduction to this thesis, the next stage of the research involves qualitative research with children to gather their views on the impact of parental IBD on everyday life and their support needs. Findings from this research were used to further refine hypotheses about the impact of IBD on parents and their children, and support needs. These hypotheses were then tested in phase two of the research: the quantitative survey of parents and children.

CHAPTER 7

Study 2 - Research Design and Methods

7.1 Introduction

Data from Study 1 provided an insight into parents' views on the impact of IBD on both themselves and on their children. However, as discussed in Chapter 1, it is widely recognised by researchers that parents are not always reliable informants on their children's views and experiences, and that it is important to gather data directly from children. Parents involved in the first stage of the research acknowledged this themselves. The following comment is taken from discussions between researchers and parents about the possibility of carrying out research with children:

> *I don't know the best way of bringing up the subject with them but yes I think it'd be a good idea to get their point of view on it because I mean we can only surmise what they're thinking. Yeah we don't know for sure what's going through their heads, you know, we can guess from their behaviour and so on but yeah I think it would be a good idea to talk to them.*
> (Study 1, parents' focus group)

Not only did parents perceive there to be methodological advantages in research directly with children, but they felt the findings might be useful to parents:

> *I think it would good for us really as well to see what they thought, to see how, what he thought of the way things are.*
> (Study 1, parents' focus group)

For these reasons, a second study was carried out in the spring of 2001, involving the children of parents who had taken part in the first study. The aim of the research with children was to investigate their perception of their parent's condition and its effects on everyday life. The objectives were to describe:

- What children know and understand about their parent's IBD
- Views on the effects of parental IBD on their everyday life (both positive and negative)
- Strategies used to cope with any difficulties experienced
- What support children feel is needed by their family

7.2 Research Sites

Given that the young people involved with the research were children of parents in Study 1, the research sites were the same. Before carrying out Study 2, a new application for ethics committee approval was sought and granted from the two Local Research Ethics Committees serving the two hospital trusts involved with the research.

7.3 Preliminary Work

Before undertaking the research, some preliminary work was necessary. First, a parent with IBD and her seven year old child were consulted about the recruitment strategy for the study, including the project information leaflets.

Second, three young people aged between seven and 14 years were recruited as advisors to the project, through members of staff at the University (see Appendix 11 for letter inviting people to be an advisor). Two young advisors were visited in their homes; one chose to meet the researcher at the University. These advisors completed a mock interview, were asked for advice on ways of making the project fun to take part in, and for their views on an information leaflet about the research.

7.4 Recruitment Process

In order for a child to be included in the study, s/he had to be aged six years or above and have a parent who had experienced symptoms of UC or CD for at least one year. There were two reasons for specifying this age range. First, research on younger children finds that it is not until the age of five or six years that children are consistently able to answer 'why', 'when', and how' questions (Steward *et al.*, 1993). Children younger than this may also have poor conceptualisation of the past tense and difficulty with open questions (Morison, 2000). Thus the questions that can be put to children under 6 years of age are

limited. Second, when the possibility of a research study involving children was discussed with parents involved in Study 1, *most* said they would agree to their children taking part in such a project, but a few parents of pre-school children were reluctant due to concerns that it would cause the child to worry about their parent's health.

Recruitment of research participants involved telephoning all parents who took part in the first study, who had a child that met the inclusion criteria, to inform them about the research and seek permission to send further information through the post. Where parents were agreeable, they were sent a letter and information leaflet about the project, plus an information leaflet and response form for every child in the family eligible for the study (See Appendix 12-15). Once a child returned a response form indicating that they were interested in taking part, the researcher telephoned him/her to discuss the research and arrange an interview where appropriate.

7.5 Method Of Data Collection

Since this was the first study of its kind, the focus in designing the study was to gain an insight into children's perceptions without presupposing what they might be. Most children were interviewed on a one to one basis. This was primarily to ensure that children had an opportunity to talk about their individual experiences. There were also ethical reasons for this approach. It emerged early on in Study 1 that some families did not talk openly about the parent's health. This meant that group interviews risked children sharing information that they would not otherwise have done.

Although it was explained to families that the researcher would like to meet with siblings individually, parents' advice as to what they felt was most appropriate was sought. In three families parents felt it would be better to interview brothers and sisters together. In two cases, this was because a parent felt that the children's curiosity would make it impossible to ensure privacy and lack of disruption. In the other, it was because one of the children was shy and the parent felt she would be more comfortable with her sibling present. For this reason, seven children aged between 6 and 10 years, were interviewed with their siblings. Children were given a choice about where to be interviewed. Most chose to be interviewed at home; three were interviewed at the University.

The content of the interview was influenced by the findings from Study 1, the research literature on the impact of parental chronic illness on children, and advice from young advisors. Furthermore, in designing and carrying out the research consideration was

given to the fact that children are better able to participate in research if their skills and preferred means of communication are taken into account (Alderson, 2000; 1995; Beresford, 1997; Boyden and Ennew, 1997), and that when interviewing very young children, data quality can be improved by giving participants an opportunity to say when they do not understand a question (Waterman *et al.*, 2001).

The interview topic guide covered:

- Introduction to young person
- Introduction to the family
- Mum/Dad and what happens when s/he is not well
- What the young person knows about the parent's health
- Things that help when Mum/Dad is not well
- Help wanted for self, parents or others in the family
- Advice to other young people whose parent is unwell

The research questions posed were the same for all age ranges, but the language adopted during the course of the interview, and techniques used to elicit data, varied according to the child's age, skills and interests. Two topic guides were drawn up: one for young people under 16 years of age, the other for those aged 16 years or older (see Appendix 16 and 17).

For children of all ages, a timeline was available to facilitate discussion about how things had changed over the course of the young person's life, and a bar graph was used to discuss how frequently a parent was unwell. In addition, children aged 6 to 11 years were given sheets of paper with topics for discussion written across the top (A bit about myself; My family; My Mum/Dad and what happens when s/he is not well; Things that help). They were encouraged to describe their experiences by drawing or writing under each of the headings. When discussing the ill parent, children were given a sheet of paper with the outline of a figure on it, which they could colour in to make it look like their parent. All interviews were brought to a close with participants being asked if they wanted to pass on any messages to other young people who had just found out that their parent was unwell. Younger children were given a 'Message' sheet to write on. Examples of visual aids are given in Appendix 18.

To gain an insight into the parents' health at the time of the interview, parents were asked to complete the SIBDQ, a measure of health related quality of life in people with IBD (see Chapter 5, section 5.5.1 and Chapter 9, section 9.9.1 for further details).

7.6 Ethical Considerations

Study 1 indicated that the research topic was a sensitive one for many families: parents varied in what they told their children about their health; they reported that some children were embarrassed about the condition, particularly in the company of people outside the family, and some were concerned the project might cause young people to worry about their health. In addition, since this study involved collecting data directly from children, there were other ethical issues to consider, namely ensuring children's safety, and informed consent. The ways in which these various ethical issues were dealt with are described below.

7.6.1 Dealing with sensitive issues

Prior to meeting with young people, the researcher contacted parents to discuss what the child knew about the parent's illness, what words s/he used to talk about inflammatory bowel disease, and how they might feel about talking about issues related to the parent's health. The researcher kept notes on advice given by parents and reassured the parent that they would not disclose information about the parent's health or use medical terms unfamiliar to the young person.

Before beginning the interview, participants were reminded that they could stop at any time, or ask to skip questions, without having to give a reason. During the course of the interview, the researcher watched for any non-verbal cues that the young person was uncomfortable about the topic under discussion and, when this happened, would move on to another topic. In situations where the young person was distressed about an issue, the researcher gave him/her an opportunity to talk about their feelings and then turned the discussion to things the young person had done, or could do, to make themselves feel better. The researcher also offered to seek out assistance from appropriate organisations.

7.6.2 Ensuring children's safety

First, arrangements were made so that the researcher had a clear plan of action should a young person reveal information during an interview which suggested they were experiencing abuse or neglect. A social worker within the University agreed to be the first point of contact should such a situation arise. Following discussion of the researcher's concerns, the social worker would advise the researcher on what to do next, and where necessary, which authority to contact. Second, the researcher carrying out the work applied to have police records checked to demonstrate that it was considered safe for her to work with children.

7.6.3 Ensuring informed consent

Throughout the recruitment and interview process efforts were made to ensure that young people fully understood the nature of the research, had consented to participate, and were clear that they could withdraw from the project at any time, without having to give a reason. After consultation with young advisors, separate information leaflets and response forms were drawn up for parents, and children aged 6-10 years, 11-16 years, and above 16 years (see Appendix 13-15). This was followed up with a telephone call to the young person to discuss what taking part would involve. Before beginning the interview, all children and young people signed a consent form (see Appendix 19), which asked them to confirm that they had read the project information sheet, reminded them they could change their mind about taking part at any time, and that all information provided would be kept confidential. When a participant was under 16 years of age, the parent's consent was also sought (see Appendix 20).

Given that confidentiality is a term likely to be unfamiliar to many children, part of ensuring informed consent was explaining it to participants. A number of steps were taken to assist with this process. First, a short contract was drawn up in which the researcher promised to keep everything the young person talked about private, unless the young person told the researcher that someone was doing something to hurt them and they might need help. This contract was signed by the researcher in the child's presence and given to him/her to keep (see Appendix 21). Secondly, it was explained that code numbers would be used instead of names to label audio-cassette and reports. Young people were given the option of selecting their own code and this was then written on the cassette. Thirdly, at the end of the interview, young people were asked what name they would like to be used in the report instead of their real name; and whether they wanted the tape of their interview, and any drawings or writing they had completed, returned to them at the end of

the project. The young person's decision was recorded on a short form (see Appendix 22).

7.7 Data Analysis

As in Study 1, all interviews were tape recorded and transcribed, and the 'framework approach' used to analyse the data (See Chapter 5, section 5.7 for further details). Two researchers were involved in the initial identification of a thematic framework. One researcher then took responsibility for charting and summarising the data. Visual and written material produced by participants was examined and any additional data not apparent in the interview transcript were added to the charts. This was rare since discussions of children's drawings and writing formed part of the interview process. Finally, the second researcher checked a summary of the findings.

CHAPTER 8

Children's Views on Having a Parent with IBD

8.1 Introduction

This chapter reports on the findings from Study 2 - the qualitative research with children. First, the findings are put into context by providing information on the response rate and the background of young people involved in study. The chapter ends with a summary of the findings, including the strengths and limitations of the research, how the data fit with findings from Study 1, and the implications for the next, and final phase, of the research.

8.2 Response Rate

Overall, the response rate was good. In total, 23 children, drawn from 15 families, took part in the study. A breakdown of recruitment according to site is given in Table 9. Two out of the 17 parents contacted about the research decided against passing information about the study on to their children. In both cases this was because the children had recently experienced upset due to a death or separation within the family, and it was not considered a good time for them to discuss sensitive issues. Out of the 25 children parents passed invitations on to, only two young men chose not to participate.

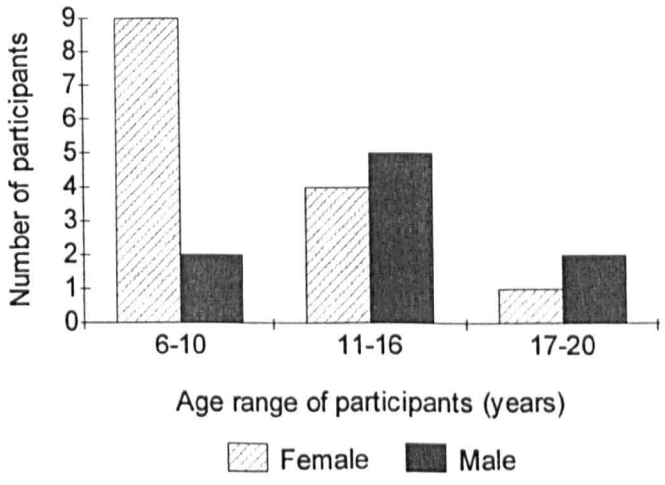
Table 9: Study 2 - Recruitment of participants

	Site A	Site B	Total
Number of families recruited	11	4	15
Number of children recruited	18	5	23

8.3. Young People's Characteristics

The young people who took part were aged between six and twenty years (median age 11 years). Fourteen were female and nine male. The age and sex distribution is given in Figure 3.

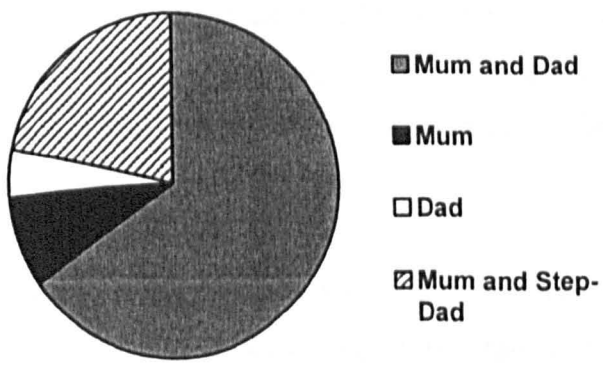
Figure 3: Study 2 - Age and sex distribution of young people



Almost all the participants were in full time education: 13 were at primary school; six at secondary school; one attended sixth form college; and two were at university. One young person worked full time.

Most young people lived with both parents; three lived with a single parent (see Figure 4 for further details on who the child lived with).

Figure 4: Study 2 - Which parent does child live with?



In 20 cases it was the young person's mother, rather than the father, who had IBD. A breakdown of the sample by parent's diagnosis is given in Table 10. Four children had a parent with an ileostomy.

Table 10: Study 2 - Parent's diagnosis and SIBDQ score

Diagnosis of parent	Number of children	Median SIBDQ score
CD	14	4.8
UC	8	5.6
Crohn's colitis	1	6.8
TOTAL	23	5.5

8.4. The Findings

There were nine major themes within the data, many of which were related to questions included in the interview topic. These were the young person's social life; perception of the parent with IBD; knowledge and perception of the parent's illness; effects of IBD on everyday life; feelings about Mum and Dad being unwell; things that help; and help wanted. Issues that emerged unprompted were talking to others about Mum/Dad's health and hospital visits. These themes are described below.

8.4.1 Young people's social lives

At the beginning of the interview, participants were asked what they liked doing in their spare time. This question was useful as a means of starting the interview in a non-threatening way and getting to know young people. However, it was also highly relevant to the research since the previous data from parents revealed concerns about restrictions to children's social activities.

Almost everyone mentioned spending time with friends. Children were also involved in a wide range of activities, some of which were solitary, (for example, listening to music; computer games; watching television; drawing; playing the guitar etc), but others were group activities (drama club, army cadets, football, volleyball, cricket) or involved a friend (snooker, table tennis, tennis etc).

Children also talked about things they did in their spare time with their immediate family. These are listed in Table 11. Five participants mentioned feeling their family did not do a lot together, but in only two cases was this attributed to the parent's illness. Other

reasons given were that parents worked at weekends or were tired after a busy week in stressful jobs. In addition, older participants commented that they sometimes tried to get out of being involved in family events.

Table 11: Study 2- Family activities

Shopping	Go to Mcdonalds	Going caravanning
Beach	Family gatherings	Watching TV
Eating together	Going away on holidays	Going for walks
Playing snooker	Cinema	Go out for meals
Fishing	Cycling	Visiting National Trust places
Computer games	Going to theme parks	

8.4.2 Perceptions of the parent with IBD

Before talking about what happened when their mum or dad was unwell, young people were asked to describe their parent. This question was included partly for ethical reasons; it was considered important not to focus solely on the parent's ill health. In addition, this question was very useful in providing an insight into how young people viewed this parent.

All young people talked about things their parents liked (for example, listening to music, crosswords, motorbikes, watching television, gardening, their job etc.) and disliked doing (e.g. aeroplanes, going to theme parks etc.). Many also chose to describe some aspect of the parent's personality. In 14 cases they listed positive attributes, most commonly that the parent was 'nice' or 'kind'. Others were that the parent was 'thoughtful', 'generous', 'brilliant', 'fun', 'caring', 'hard working' and 'lovely'. Only one young person choose to refer to the parent's illness, explaining that he was nice but got cross and 'really mad and touchy' when ill.

Eight young people chose to talk specifically about what a good parent their mum or dad was. Sometimes this was about the practical things the parent did for their child. For example:

> *If you ever need owt, you just ask and she's got it there for you, she's brilliant.* (age 16)

Other young people spoke about how their parent was always there for them, loving, and caring. For example:

> *She's definitely caring. She always says 'I love you' before I go out, just in case I get run over! She always shouts out in the street 'I love you, see you tonight'. She's very thoughtful, always makes sure my pack up is ready, makes sure I got to bed early ...it's a bit embarrassing sometimes really.* (age 16)

Five young people spoke about their relationship with their parent. All but one described their relationship in very positive terms. For instance, one said ' my mum is my friend' (age 8 years), another simply ' I love my mum' (age 10 years). The one young person who was not so positive, said that he had not been close to his parent as a child, since his parent found it difficult to relate to young children, but that they had grown closer as he had got older.

Finally, a few people mentioned things they did not like about their parent. This included being made to tidy their room, having to ring to say where you are when out with friends, and being teased. One young person did not like that her parent often did not stand up for himself.

In terms of understanding the impact of IBD on parents, these findings are significant in that the aforementioned positive descriptions included parents who had at times been very unwell.

8.4.3 Knowledge and perception of the parent's illness

Children varied a great deal in how much they knew and understood about their parents' health, even when they were from the same family. During the course of the interview, eight young people, all aged 10 years or older, referred to their parent having 'ulcerative colitis' or 'Crohn's'. Younger children tended to refer to their parent having a 'poorly tummy'. Two young people whose parent had an ileostomy referred to their parent having a 'bag'.

A number of young people, including those who had used the terms ulcerative colitis and Crohn's, said they did not know anything about their parent's health. Others made suggestions which indicated some understanding of their parents' condition:

If she eats something her belly can't take it and it goes straight through (age 11)

Some participants talked about how their understanding had increased as they got older. However, variations in understanding did not simply reflect age differences since there were examples of younger children knowing more than older children, even when they were from the same family.

The way in which people found out about their parent's illness differed depending on when their parent became ill. In some cases, the parent had become ill while the child was growing up, so s/he had noticed the parent suddenly going to the toilet a lot, complaining of stomach pains, and visiting the doctor. Many young people explained that their parent had always been unwell, so they 'just knew' through the parent being too tired to play with them when they were younger, noticing that their parent could not do the same things as other parents, through overhearing conversations between their parents, or noticing the other parent being worried and over-protective of the ill parent. A few parents were said to have spoken to the child about their health, but others said no one had ever told them about it.

Children had mixed views on how serious they felt their parent's illness was. Four young people were clear that they did *not* feel that their parent's illness was at all serious. Three of these children had a parent who had an ileostomy. The fourth, whose parent's SIBDQ score (3.6) suggested she had recently been quite unwell, said:

> *I don't think it's really serious, I just think if she was better we would have more fun.* (age 7)

Five young people were clear that their parent's illness was serious. Reasons included the belief that the condition could have been much worse, but the parent was lucky enough to have been treated in time; that the condition was very disruptive to every day life; and concerns that the parent might have to go into hospital or might die.

Other young people stated that it was both serious and not serious. In making this qualification, a number of young people, aged 11 years or older, referred to the fact that the condition was not life-threatening, but did affect every day life:

I think it's quite serious, well not life-threatening, but serious in that it almost ruined his life because he's not as happy as he might be if he didn't have it...it's serious in the sense that it's basically permanent, it's not as serious as something like cancer, but it's quite serious. (age 11 years)

8.4.4 Talking to others about Mum/Dad's health

Children differed in how much they talked to parents about IBD. At one extreme, a young man aged 16 years, whose mother had CD all his life, said he had never spoken to either of his parents about why she was sometimes ill. At the other end of the scale, another young man said his mother discussed everything the doctor told her with her family. Five young people explained that they preferred not talk to the parent who was ill about their health. Reasons given were that it was embarrassing and/or upsetting for the young person; that they did not want to add to their parent's worries by letting them know they were upset; and that the parent was not comfortable talking about it.

Children also had different views on whether you should talk to friends. Four girls, aged between 9 and 14 years, spoke of talking to friends when they were upset or worried about their parent. For example:

I have quite a lot of friends that understand me and I know I can talk to any one of them and they'll understand. Sometimes I get really upset about things and it makes me happier. (age 11 years)

However, another six mentioned that they avoided talking to friends or other people their age about their parent's health. In some instances, this was simply because the young person felt there was no reason to because their parent was reasonably well. Others suggested that friends would not understand, or were concerned that friends would make fun of them. As one 10 year old explained:

No point telling them cause they wouldn't understand cause they haven't got a mum with Crohn's. People spread and talk to other people. We like to keep it quiet.

Two young men said that, while they might talk to people now about their parent's health, it was something they had chosen to keep quiet when younger because they might be teased.

8.4.5 Everyday life and IBD

A number of young people felt that their parent's health made little or no difference to their everyday life, usually because the parent's health was good. In addition, one young person explained that, now that he was older, he spent most of his free time involved with part time jobs, hobbies and friends, so rarely spent time with the parent who was unwell.

Just three young people were able to think of positive effects of their parent's illness. These were the parent reading to the child when ill in bed; a young person very occasionally being allowed to make his own dinner; and the possibility that the family had been brought closer together by supporting the parent through a difficult illness.

The most frequently reported negative effect on everyday life was restrictions to social activities, with eleven young people mentioning restrictions. However, it is important to note that the level of restriction, and extent to which young people were bothered by it, varied considerably, from:

> *At weekends we can't go really far in the car, but it's not a big deal. We still go abroad. She just takes a lot of pills when we're doing that.* (age 13)

To:

> *It makes a difference to everything. If there are toilets it's not too bad, but she can't eat out, she can't go out, she can't go on holidays, she runs to the toilet all day and she's just really tired. I can't remember going out for a meal with my mum or dad. I'd like to take her to the cinema, we never go to the cinema...she did go to school sports day when I was younger, she could do that.* (age 16)

In a few cases, social restrictions experienced were due to the young people *choosing* to stay at home to make sure their parent was alright:

> *I would stay at home rather than going out with friends. It's not that she needs help, it's just I'd rather be around* (age 13)

In a number of instances, children explained that family social events were not cancelled, but that the parent would not be involved.

Some young people noticed that the parent was unable to cook or clean. Usually the other parent took on more responsibility, with children helping out. There were also a couple of instances where tasks were simply left for the ill parent to do when recovered. None of the young people felt that the tasks they were asked to take on were unreasonable, though there were some complaints about responsibility not being shared equally amongst siblings.

A number of children talked about how they had to be well-behaved when their parent was ill. For example:

> *We have to be very quiet, not arguing, and sometimes we have to go upstairs and play in our bedroom and I don't like it.* (age 8)

They also spoke about changes to the mood of members of their family when their parent was unwell, with the parent with IBD not talking to them as much, or becoming cross or bad tempered. In a couple of cases, the other parent was also reported to become stressed and bad tempered. One young person said that the whole family tended to become edgy and nervous when the parent complained of any symptoms since they immediately worried that it might be the start of another flare up.

Just two young people mentioned that their parent was sometimes not able to take them to school, but in both cases it was easy to make alternative arrangements.

In a few families, young people were looked after by others (neighbours, friends, grandparents, or aunts and uncles) while their parent was ill. This could be viewed positively or negatively, depending on how the young person knew and got on with the people involved.

8.4.6 Hospital visits

Just over half the young people spoke of what it was like to visit their parent in hospital. A number said there were positive aspects to visiting their parent, such as being given sweets and crisps, being bought things from the hospital shop, meeting other people in the hospital who were nice, and finding out how your parent was, rather than sitting at home worrying about them. For instance:

We go to see her a lot. It's good going in cause I like Mummy. Also, she has packets of crisps and sweeties and grandma buys us things from the shop. (age 8)

And

I visit him every night when I am at school, or during the day if I can visit him, cause I just feel happier than to be worrying at home, not know what's happening, I prefer to just go and see how he is. (age 11)

Others did not like hospital visits, explaining that it was not nice to see your mum or dad poorly, or that it reminded them of times when they had been to hospital for treatment. For example:

Didn't want to go because it reminded me of the time when I had to go to hospital for stitches and I was scared. I was upset because she was asleep and it reminded me of times when she was poorly and getting tired a lot, which wasn't nice. (age 8)

One young person recalled that when he was young he liked visiting mum, but did not like leaving her since he worried that she would not be coming home.

A parent being in hospital also made a difference to life at home. A few people said it was strange not having the parent around, especially at meal times. It also meant there were more chores, like washing up and cooking, for other people in the family to do. One child was pleased to be allowed to stay up late and sleep in her parents' double bed when her father was in hospital.

8.4.7 Feelings about mum or dad being unwell

Participants were asked how they felt about Mum or Dad being unwell. Eight young people were unconcerned. Reasons given were that their parent was not often unwell, they were aware that the illness was not life-threatening, and/or the illness was just a normal feature of everyday life. For instance:

Not bothered about it. She has been in hospital but wasn't bothered about it. She isn't seriously ill. (age 13)

The most common feeling was being 'sad' or 'upset', with ten young people using such words to describe how they felt. This feeling was due to seeing their parent poorly; the belief that a parent would not return home from hospital; the parent not being able to go out or on holidays; and the belief that the parent might die. Almost as many spoke of being 'worried' or 'scared'. Reasons given were general concern about the parent's health; confusion brought about by disagreements between parents about what the ill parent could manage; fears about what might happen during an operation; fears about the possibility that the parent might die; and fear of visiting their parent in hospital. One young person, who had a parent and a grandparent with IBD, spoke about concerns that she and her children might also develop the condition.

Feelings of guilt about the parent's illness were expressed by two young people, due to the belief that condition was stress-related and therefore they might be to blame, or incidents where the parent became unwell after taking part in activities with the child that he had been advised to avoid.

Three children spoke of feelings of anger, describing times when they had thrown things around their room, or screamed and shouted in front of others. This was due to dwelling on what it would be like if the parent died; having to stay indoors to keep the parent company; restrictions placed on the family's diet because of the parent's health; feeling that better treatment should be offered by doctors; and annoyance that a parent was erratic in taking and storing medication safely.

Feelings fluctuated over time depending on what was happening with regard to their parent's health and treatment, and the child's age. As a result, for most young people negative feelings were transient. However, in a few cases, comments suggested that the worry was more pervasive. For example:

> *When he's not well, I start mothering him and say things like 'Dad, you should go into hospital'. I copy Mum. It sounds funny, but I'm very serious, I get a bit anxious.....I worry quite a bit'.* (age 11)

One young person explained that she would often spend all day at school worried how her parent was managing at home, and another that worries led to frequent nightmares.

8.4.8 Things that help

Children who described negative feelings or reactions, were asked what they, or anyone else, did that made them feel better. Participants were also asked about things that helped the parent. Findings in relation to both issues are described below.

Things that help the child

A few said there really was nothing they could do to make themselves feel better since they could not alter the fact that their parent was ill. When strategies were reported, the most popular was trying to forget about the situation by doing something else, such as watching television; playing with brothers and sisters; phoning or sending text messages to friends; listening to music etc. For instance:

> *I get myself into bed, at times I do, and read a book and go to bed, and every night I watch TV so that sort of puts me to bed.* (age 7)

A number of young people, all female, spoke about talking to friends. For example:

> *I have a lot of friends that understand me and I know I can talk to any one of them and they will understand. Sometimes I get really upset about things and it makes me happier.* (age 11)

A few said having information about their parent's health and medical treatment was helpful. Examples given included seeing a television programme about the surgery the parent was about to undergo, the purpose of an oxygen mask being explained, and being told that the illness was not your fault.

Other things that helped were having a friend in a similar situation (since it makes you feel less alone), other people calming you down, and very young children spoke of hugging their cuddly toys.

Things that help the ill parent

Young people were aware of the efforts made by the ill parent to cope with the condition. These included: taking medication; resting; eating or drinking the right things; having homeopathic treatment; going on holiday; taking their mind off it by working, reading, or watching television; pushing the family to go out and enjoy themselves without the parent; and just trying to carry on with life as normal.

Children also spoke about a wide variety of things they, and others, did which helped their parent. In terms of things that children did to help, the most frequently cited method was doing more around the house. Eleven young people mentioned this, but most said it was 'no big deal', consisting of the odd jobs such as washing up dishes, setting the table, making snacks or other tasks that were not too difficult to do. Tasks seemed to differ according to age. For example, while a teenager spoke of cooking meals, primary school aged children spoke of simpler tasks, such as heating food up in a microwave.

A few said that when their parent was unwell, they preferred to stay at home to make sure s/he was alright. Some participants spoke of not wanting to bother the parent when ill, so staying out of the way, or making efforts to ensure peace and quiet. For example:

> *If she's not well we will say to each other to keep it down. We call it a Crohn's day, she's having a Crohn's day* (age 16)

Other less frequently mentioned ways of helping were trying to appear happy even if you do not feel it; talking about things that took the parent's mind off the illness; giving the parent hugs and kisses; asking how the parent was; and making the parent laugh.

Practical and emotional support was also provided by the other parent, siblings who had left home, family friends, aunts and uncles, grandparents, and neighbours. Three young people mentioned service providers. They were aware that medical treatment played an important role in their parent's health, and of resources provided by social services.

8.4.9 Help wanted

Aside from the ill parent being completely better, there was little help that young people wanted for either themselves or their family. Many stated that their family was managing well. Four participants said they would like more information on IBD, what was happening to their parent, and/or advice on how to behave around their parent. However, three young people, who felt their parent's health was good, said they really were not interested in receiving further information. A few young people were keen to meet others who had a parent with IBD, but many more were not keen on this idea when it was put to them. One participant wanted some way of enabling his parent to get out of the house more often. Another said help with housework would prevent the parent working too hard and making himself ill.

8.5 Summary Of Findings And Implications For Future Research

Since this is the first study involving young people who have a parent with IBD, children were given broad topics to discuss and, within this framework, had the opportunity to tell their story. This was very useful in giving younger children a voice, something that has been largely absent from research on parental chronic illness.

Nevertheless, the data are limited in a number of ways. First, the data represent what participants *chose* to talk about. After an interview with one young person, a parent commented that she wondered how much her child would have said about what happened at home. The parent explained that she was incontinent and occasionally had 'accidents', which her child had promised to keep a secret from others. It is perhaps not surprising that this young person did not mention such incidents during the interview. It may be that there are other experiences which young people in this study chose not to speak about. For example, it is notable that although parent's reported that children were embarrassed by the symptoms of IBD, this does not emerge as an issue within the children's data. It is possible that discussing this issue with a researcher was in itself embarrassing for young people, so they chose not to.

Second, as well as being asked about current experiences, young people talked about experiences over the course of their life. It is difficult to assess how closely young people's memories of events and feelings match experiences at the time.

Third, although 23 young people took part, they were drawn from just 15 families. In only three cases was the parent with IBD the father. With such small numbers involved in the research it is difficult to draw conclusions about factors that influence children's experiences, particularly whether there is a difference between the impact of having a mother and father with IBD.

Finally, the age range of the young people who took part limits the conclusions that can be drawn from this study. Many of the difficulties parents reported during Study 1 were specific to pre-school children. This study omits the experience of these children, with the youngest participant six years of age.

Turning to the findings, some young people were unaffected by their parent having IBD. However, where the illness was severe, and parents were experiencing inpatient hospital treatment, there were disruptions to domestic routines, and increased irritability by both

parents. Although there were restrictions to social life, they were often not problematic for adolescents since they did not necessarily want to spend their free time with parents. In addition to this, a number of factors helped to reduce the impact of social restrictions. First, many younger children spoke of how the ill parent would stay at home at weekends and during holidays, but that they went out with the other parent, relatives, and family friends. Second, when children lived in a neighbourhood where there were other children it was possible for them to 'play out with friends'. Finally, older children of secondary school age and above were not reliant on their parents to organise their social life with peers.

Aside from aforementioned difficulties, young people reported feelings of upset, worry, and anger. In some cases they attempted to keep these feelings hidden from parents. Young people were in agreement with parents as to the main reasons for emotional upset. These were seeing the parent particularly unwell and/or hospitalised and, less frequently, restrictions to family life. There was some evidence to suggest younger children were more prone to worrying about the parent's health and medical treatment, with young children mentioning worries over hospitalisation and/ or that their parent might die, whereas children aged 11 years and older understood that IBD is not a life-threatening condition and that hospital treatment would make the parent better.

The research with children highlighted an issue not mentioned by parents: that some young people feel guilty about their parent's ill health, either because the parent had taken on more child care tasks than s/he could manage, or due to the belief that the illness is stress-related.

A few young people felt there were positive aspects to their parent having IBD, including the parent spending time reading to a younger child whilst ill in bed; being allowed to make your own meals; and the development of closer relationships within the family. It is important to note that overall children spoke with warmth about the parent with IBD. This suggests that, even if a parent is in poor health and struggling with parenting responsibilities, it is still possible for there to be a close relationship between the parent and child.

Compared to parents, children had few support needs. Just a few young people suggested that it would be useful to have someone to talk to about how to deal with their situation, an opportunity to meet other young people who have a parent with IBD, and help with housework. In Study 1 participants debated whether it was a good idea to talk to

their children about their condition, with parents sometimes holding opposing views on this matter. The research with their children did not offer any answer to this question as there was no clear link between whether children spoke to their parent about their health and perceptions of illness severity or feelings of worry. However, children whose parents had more severe symptoms appeared to have a greater need for information, and the few who had received explanations as what was happening to their parent when in hospital found this helpful.

In the next phase of the research, these findings will be used to guide the selection of variables for inclusion in the survey of parents and children, and the development and testing of a conceptual model explaining the impact of parental IBD on children's psychological well-being. Finally, experiences in this study suggest that when developing survey materials it should not be assumed that children will be familiar with or understand medical terms, such as 'inflammatory bowel disease', 'Crohn's' and 'ulcerative colitis'.

Part IV

Phase Two of the Research

CHAPTER 9

Phase Two: Research Design and Methods

9.1 Introduction

The qualitative research reported in previous chapters provided an insight into the potential impact of inflammatory bowel disease (IBD) on parents and their children, and the support families might find useful. However, it is unclear to what extent these views are shared by the general population of families in which a parent has IBD, or which factors influence the effects experienced. The next phase of this research involved a cross-sectional postal survey of parents with IBD, and their children, to investigate these matters. This chapter describes the aims and objectives of the survey, inclusion and exclusion criteria, sample size, the sampling frame, the recruitment process, efforts made to reduce non-response, ethical considerations, the method of data collection, and data analysis.

9.2 Aims And Objectives

The overall aim in carrying out the survey was to investigate the support needed by parents with IBD and their children. It was both descriptive and analytical in nature. First, in relation to the descriptive element of the survey, the research objectives were as follows:

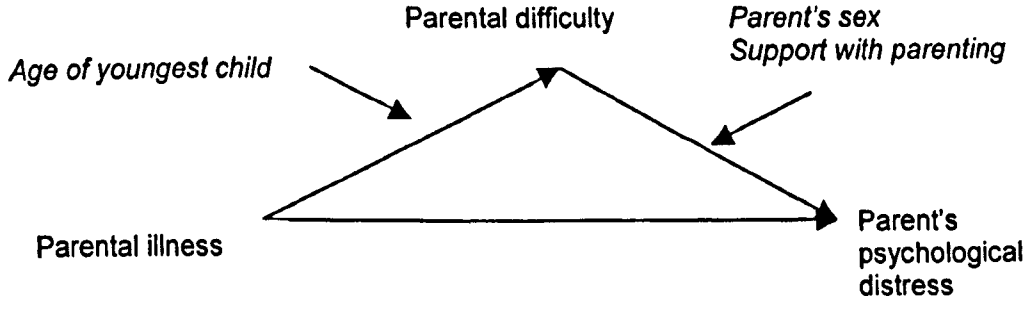
- To describe the extent to which parents with IBD experience difficulties with parenting tasks and psychological distress, and the support they receive from others in relation to parenting.
- To describe children's responsibilities within the home, social activities with peers, relationships with parents, and psychological adjustment.
- To compare parents' psychological distress and children's emotional and behavioural adjustment with normative data from the UK population.
- To identify parents' and children's met and unmet support needs.

Second, in relation to the analytical element of the survey, the research objective was:

- To investigate factors that moderate and mediate any psychological distress experienced by parents with IBD and any emotional and behavioural difficulties experienced by their children.

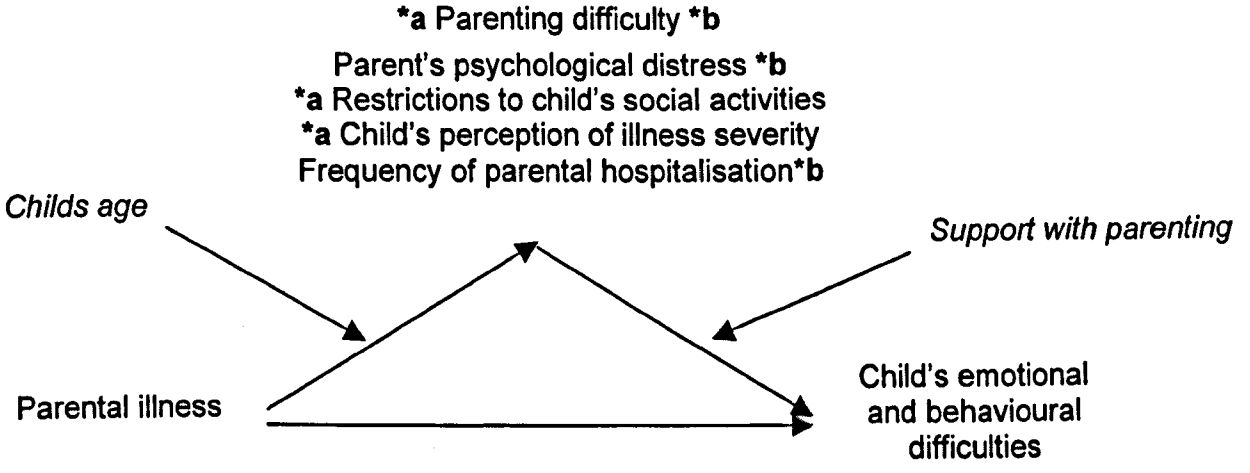
Based on the literature reviews described in Chapters 2-4, and the results of studies 1 and 2, two conceptual models, describing moderators and mediators of parents' psychological distress and children's emotional and behavioural difficulties were developed. The conceptual models are described below.

Figure 5: Conceptual model of impact of IBD on parents' psychological distress



In the parent model, it is hypothesised that IBD leads to increased parenting difficulties, which in turn mediates psychological distress. The age of the youngest child in the family moderates parenting difficulty, with parents of younger children experiencing greater parenting difficulties. In addition, the impact of parenting difficulty on parent's psychological distress is moderated by the parent's sex and support with parenting. It is predicted that parenting difficulty will lead to greater distress in mothers than fathers, and in those who have less support.

Figure 6: Conceptual model of impact of parental IBD on children's emotional and behavioural difficulties



*a = variables affected by the interaction between parental illness and child's age
*b = variables moderated by support with parenting

In the conceptual model of children's emotional and behavioural difficulties, parental illness per se does not lead to children's difficulties. Instead, it is hypothesised that difficulties are mediated by:

- Parenting difficulties
- Parent's psychological distress
- Restrictions to the child's social activities
- The child's perception of the severity of the parent's illness
- The child's experience of parental hospitalisation

The model also specifies moderators:

- The age of the child

The child's age will interact with disease severity, with younger children experiencing more restrictions to social activities and perceiving the illness as more serious. In addition, as stated in the parent model, parents of younger children will have greater difficulty with parenting tasks.

- The parent's support with parenting

Lack of support with parenting will interact with parenting difficulties, parent's psychological distress, and parental hospitalisation, increasing children's emotional and behavioural difficulties.

9.3. Inclusion And Exclusion Criteria

The inclusion criteria for parents involved in the study were that the parent had:

- A diagnosis of ulcerative colitis or Crohn's disease;
- Symptoms for at least one year;
- A child living at home aged between 0 and 16 years of age.

The inclusion criteria for children were that they had a parent who met the inclusion criteria stated above, and were aged between 11 and 16 years. There were no exclusion criteria. However, since there were no resources for translating written materials, it was likely that the survey would exclude parents who are not proficient in English.

9.4 Sample Size

To ensure that the study sample size was adequate for the various elements of the analyses, a series of power and precision calculations were carried out. These calculations were based on the primary outcome measures: parents' psychological distress and young people's emotional and behavioural difficulties. For each calculation, alpha was set at 0.05. Calculations were carried out using a computer program for statistical power analysis and confidence intervals – 'Power and precision' (Borenstein *et al.*, 2001). Full details of output from these calculations are given in Appendix 23. A summary of the findings, and the conclusions drawn regarding the sample size needed for the survey, follow below.

9.4.1 The prevalence of psychological distress in parents

Parents' psychological distress was assessed using the Hospital Anxiety and Depression Scale (HADS) (See section 9.9.1 for further details). In a recent survey of a UK community sample using this scale (Crawford, 2001), 33.2 per cent of the sample had mild to severe anxiety, and 11.4 per cent had mild to severe depression, based on Snaith and Zigmond's (1994) criteria for caseness. Therefore, within the study population, 66 per cent or more of the sample reporting case level anxiety would be of interest, representing

double the rate found in the community. In order to detect this effect, with a power of 90 per cent, a sample of 24 parents is required. Similarly, if 22 per cent or more of the study sample reported mild to severe depression, this would be of interest since it represents double the rate found within the community. In order to detect this effect, with a power of 90 per cent, a sample of 117 parents is required.

9.4.2 The prevalence of emotional and behavioural problems in children

Children's emotional and behavioural problems were assessed using the Strengths and Difficulties Questionnaire (SDQ) (See section 9.9.3 for further details). The SDQ produces an 'impact score', which is an indicator of whether difficulties are at case level and may require clinical intervention. In Meltzer' *et al's* (2000) national survey of young people in the UK, 16.6 per cent of children aged 5 to 16 years had probable or definite case level emotional and behavioural difficulties, based on parent-reported SDQ impact scores. Therefore, within the study population, if 34 per cent or more of children have case level difficulties this would be of interest, representing double the rate found in the community. In order to detect this effect, with a power of 90 per cent, a sample of 68 young people is required.

In addition to parent-reported SDQ impact scores, self-reported SDQ impact scores were collected from 11-16 year olds. In Meltzer *et al's* national survey of young people in the UK, 13.1 per cent of 11-15 year olds reported probable or definite case (Meltzer *et al.*, 2000). Therefore, if 26 per cent or more of young people involved in the study reported probable or definite case level difficulties, this would be of interest, representing double the rate found in the community. In order to detect this effect, with a power of 90 per cent, it is necessary for 96 young people to complete the SDQ.

9.4.3 Regression analysis

Finally, to test the conceptual model of the impact of IBD on parents' psychological distress and children's emotional and behavioural difficulties, multiple regression analysis will be employed. It is recommended that regression analysis include no more than n/10 variables, where n is the sample size (Altman, 1991). Since no more than 20 variables will be entered into the regression at any one time, a sample size of 200 would be sufficient for this part of the study.

In summary, it was estimated that while a sample of 117 parents and 96 young people is sufficient to carry out the descriptive elements of the survey, in order to carry out the regression analysis, a sample of 200 parents and 200 young people should be aimed for.

9.5 The Sampling Frame

Hospital gastroenterology clinics were selected as a sampling frame for a number of reasons. First, although General Practitioners are increasingly involved in the long term care of patients with IBD, the condition is largely managed by specialists (Rubin *et al.*, 2000). Second, it was thought likely that clinics would provide a sample that is reasonably representative of the general population of patients with IBD since a survey of members of NACC found no differences between people who attended hospital-based services, and those who did not, in relation to sex, social class or type of IBD. However, it should be acknowledged that a slightly higher proportion of responders with more severe disease (82.5 per cent) attended hospital than those with milder disease (72.9 per cent) (Walters, 2000). Finally, on a practical note, it would be very difficult to recruit participants through sources other than hospital clinics, such as general practice, since IBD is relatively uncommon.

Four clinics, located throughout England, agreed to assist with recruitment. Clinics were stratified to cover a range of different geographical populations, including metropolitan, urban, and mixed constituencies (rural and urban). The clinics include both secondary and tertiary-based services, thus ensuring parents with a wide range of disease severity were represented. Approval for the study was secured first from the Multi-Centre Research Ethics Committee (MREC), and then from local NHS research ethics committees.

Shortly in to the recruitment process it became clear that it would not be possible to recruit a sufficient number of people from the four hospital clinics to meet the sample size requirements of the study. Therefore, NACC was approached for assistance and the survey opened up to their members. The intention was to randomly sample within clinic and NACC lists. However, such a small number of patients and NACC members were identified as meeting the study inclusion criteria that it was necessary to invite all those who were eligible to take part. Therefore, the final sample is best described as a convenience sample.

9.6 The Recruitment Process

Hospital-based clinics and NACC adopted different recruitment methods to fit with what was convenient for their respective organisations. These methods are described below.

9.6.1 Recruitment through hospital clinics

In hospitals, the first step was to identify patients who met the survey inclusion criteria. All patients aged between 18 and 65 years, who had a diagnosis of IBD, were sent an information sheet explaining the study and a short screening questionnaire asking for basic information on their health and family circumstances (see Appendix 24). In order to maintain patient confidentiality, clinic staff passed on the information sheet and screening questionnaire to patients on the researcher's behalf. In two clinics, where there was a list of patients with a diagnosis of IBD, this was done by post. In the remaining two clinics, where such a list was not readily available, information sheets and questionnaires were given to patients when they attended an outpatient clinic.

Screening questionnaires were returned directly to the researcher. On identifying a respondent who was eligible for the study, and had consented to receiving the questionnaires, the researcher posted out the parents' survey pack. This contained an information sheet, the survey questionnaire for parents, and a pre-paid envelope (see Appendix 25). When a parent had a child aged 11-16 years living at home, they were also sent a survey pack for every child in this age range, and asked to pass it on to the child on the researcher's behalf. The survey pack for 11-16 year olds (see Appendix 26) contained an information sheet written for young people, a questionnaire for young people, and a pre-paid envelope so that the child could return the questionnaire directly to the researcher.

9.6.2 Recruitment through NACC

In order to recruit parents through the voluntary sector, a short article was placed in the June 2002 edition of the NACC newsletter informing readers about the survey, and asking them to contact the researcher if they were interested in the research (see Appendix 27 for a copy of the article). All those who responded were sent a screening questionnaire and information leaflet. Once the screening questionnaire had been returned to the researcher, the recruitment process was the same as for the clinic sample.

9.7 Reducing Non-Response

Efforts to reduce non-response to the survey were based on a recent systematic review of 292 trials aimed at identifying strategies that increase response to postal questionnaires (Edwards *et al.*, 2001). The review found that the odds of response were double when the questionnaire asked questions particularly relevant to participants. Given that the survey asks about issues that are of concern to parents with IBD, it was hoped it would be of interest to potential participants. Care was also taken with aspects of questionnaire appearance known to aid response: questionnaires were printed on coloured paper and brown response envelopes were used. In the information leaflet, respondents were offered a short report on the survey findings as an incentive for completing the questionnaires. Finally, parents who did not respond to the survey were sent up to two reminder letters. The second reminder included a further copy of the questionnaires. Responders and non-responders to the survey were compared on data available from the screening questionnaire to assess the effect of non-response. The findings of this analysis are reported in Chapter 9.

In addition to the above, special efforts were made to ensure that the survey of children was appealing to 11-16 year olds and their parents. To achieve this, a cartoonist was involved in illustrating the questionnaire and information leaflet. Care was also taken to ensure that the questionnaire did not refer to 'inflammatory bowel disease', 'Crohn's disease', or 'ulcerative colitis', since these terms might be unfamiliar to young people.

A small group of parents with IBD (n=5), and their children (n = 2), as well with one young person whose did not have a chronic illness, were recruited as advisors to the study. The researcher met with these advisors on an individual basis to consult them about the content and format of the questionnaires and information leaflets.

9.8 Ethical Considerations

In order to ensure informed consent, information sheets for both parents and young people explained why the research was being carried out, what would happen to the data, and stressed that people were under no obligation to take part in the research, nor would their decision affect the services they received in any way (see Appendix 24-26).

Written consent to receiving questionnaires was obtained from parents when they completed the screening questionnaire, indicating that they were willing to receive the

survey questionnaires. Parents and children consented to participating in the study by completing and returning the survey questionnaires. Parents' consented to their child participating by passing the questionnaire on to the child on behalf of the researcher.

In relation to data management and storage, to ensure that all data remained anonymous, participants were assigned a code number. Separate computers, were used to store records linking the participant's code number with their name and address. All paper copies of completed questionnaires were stored in a locked filing cabinet for the duration of the study. Once the research is complete these questionnaires will be destroyed.

9.9 Methods of Data Collection

As explained previously, three separate questionnaires were administered during the course of the survey: a screening questionnaire to identify parents eligible for the study; the survey questionnaire for parents; and a survey questionnaire for children aged 11-16 years. The questionnaires included a number of standardised scales, as well as checklists and questions designed by the researcher. The decision over which measures to include was strongly influenced by this being a postal survey using self-completion questionnaires, thus limiting the number of questions that parents and children could be expected to answer.

The survey of children was limited to those aged 11- 16 years for two reasons. First, the primary outcome measure for children (The Strengths and Difficulties Questionnaire) is only standardised for 11-16 year olds. Secondly, it seemed unlikely children under the age of 11 years would be able to complete forms without some assistance from parents, making the validity of data from this age group questionable.

The survey questionnaires were pre-tested on the parent and child advisors previously mentioned (see section 9.7). After completing each section of a questionnaire, the person was asked to explain how he or she understood the questions, and what they liked and did not like about them. Gastroenterologists and nurses from the clinics involved with the research were also consulted about the content and format of the questionnaires.

A summary of the measures included in each questionnaire is given in Table 12. The measures are described in detail below.

Table 12: Content of survey questionnaires

Screening questionnaire for people with IBD

Variables assessed	Method of assessment
Age of patient	Question developed by researcher
Sex of patient	Question developed by researcher
Time since diagnosis	Question developed by researcher
Presence of ileostomy or ileoanal pouch	Question developed by researcher
IBD diagnosis	Question developed by researcher
Age of any children	Question developed by researcher
If child is living at home	Question developed by researcher

Survey of parents

Variables assessed	Method of assessment
Duration of IBD symptoms	Question developed by researcher
Frequency of hospitalisations for IBD	Question developed by researcher
Frequency of times had surgery for IBD	Question developed by researcher
Frequency of outpatient appointments in past year	Question developed by researcher
Medication prescribed over past year	Questions developed by researcher
General perception of health	Question from BHPS Wave 9
Perceived IBD-related health status	Standardised measure: 'SIBDQ'
Presence of other illnesses/disability	Question from UK census 2000
Parental psychological distress	Standardised measure: 'HADS'
Difficulties with parenting	Standardised measure: 'PTI'
Met and unmet service support needs	Checklist developed by researcher
Support with parenting	Standardised measure: 'FSS'
Child's physical health	Question developed by researcher
Child's psychological adjustment	Standardised measure: 'SDQ'
Whether partner has illness/disability	Question from UK census 2000
Household socio-economic classification	Standardised measure: 'NS-SEC '
Perception of financial situation	Question from British Household Panel Survey (BHPS) Wave 9
Parent's highest educational qualification	Questions from UK census 2000
Single parent/ living with partner	Question developed by researcher
Division of domestic labour	Questions from BHPS Wave 9
Ethnic group	UK National Statistics Standard Classification

Survey of children aged 11- 16 years

Variables assessed	Method of assessment
Perception of parent's health	Question developed by researcher
Extent to which has talked to parent about IBD	Question developed by researcher
Involvement in helping parent with domestic and caring tasks	Checklist developed by researcher
Number of hours housework per week	Question from BHPS Wave 4
Perception of housework	Question developed by researcher
Level of social activity with peers	Questions from Meltzer survey
School absence due to parental illness	Question developed by researcher
Perception of family relationships	Questions from BHPS Wave 9
Psychological adjustment	Standardised measure: 'SDQ'
Child's met & unmet support needs	Checklist developed by researcher

9.9.1 Parent-completed measures

Parent's health

Parent's health was assessed in a number of ways. First, their IBD diagnosis was assessed via self-report. Previous research involving the Crohn's and Colitis Foundation of America has shown a 98% correlation between self-reported IBD and the presence of probable or definite disease by endoscopic, radiographic or histological criteria (Baird *et al.*, 1990).

Until recently, within research on IBD, health status was usually assessed via clinical activity indices (Sostegni *et al.*, 2003). However, it is now argued that these are relatively crude measures of health status since existing measures are not sensitive enough to assess the full impact of the disorder on the individual (Drossman, 1996). Furthermore, since clinical indices require the involvement of the patient's physician in data collection, self-completion HRQoL questionnaires are a practical alternative when carrying out a postal questionnaire). Therefore, in this survey, the disease specific HRQOL measure - the SIBDQ (Irvine *et al.*, 1996) was used to provide a measure of IBD-related health status.

The SIBDQ is a ten item questionnaire, which assesses IBD patient's subjective health status and quality of life over the previous two weeks and is based on the The Inflammatory Bowel Disease Questionnaire (IBDQ). The IBDQ is fully standardised (Irvine *et al.*, 1994; Mitchell *et al.*, 1988; Guyatt *et* al., 1989), and is considered the 'gold standard' for assessing quality of life in IBD (Sastegni *et al*, 2003), but is too lengthy for inclusion in a postal survey. The SIBDQ was developed by applying step wise regression analysis to IBDQ data obtained from 149 CD patients, to identify the two items which best predict the overall IBDQ score, and two items which best predict each of the four IBDQ dimensional scores (bowel symptoms, systemic symptoms, emotional function, and social function). The SIBDQ is scored on a seven-point scale, with 1 indicating poor health and 7 being optimum health.

The validity, reliability and responsiveness of the SIBDQ were assessed in 150 patients with CD and 45 with UC (Irvine *et al.*, 1996). It explained 92 per cent of the variance in IBDQ scores in CD patients, and 90 per cent of the variance in patients with UC, thereby providing evidence of construct validity. It was also reliable in patients with stable CD (test-retest reliability coefficient 0.65). Evidence of discriminant validity was provided by

its responsiveness to change in disease status of CD patients who had relapsed in the first eight weeks of the trial. As the mean SIBDQ decrease was 0.93 (p=0.001) on relapse, the authors suggest that an average per item change of one point represents a clinically important worsening of the patient's condition. Further validation of the measure for use with UC patients was recently carried out, and a moderate to strong correlation found between the SIBDQ and two disease activity indices (r=-0.83 and –0.61) (Jowett *et al.*, 2001). Significant differences in SIBDQ scores were also found between those assessed as being in remission and those having a relapse, based on physician and patient perceptions, and disease activity indices.

As the SIBDQ only provides information on perceived health status and quality of life over the previous two weeks, after consultation with gastroenterologists and specialist nurses, a series of other questions were included to gauge disease severity over a longer period of time. These covered the frequency of hospitalisation, surgery and outpatient appointments for IBD, and whether the person was prescribed steroids or immunosuppressants for IBD during the previous year. In addition, a general question on overall perception of health, previously used in the British Household Panel Survey (BHPS), was included.

Finally, parents were asked whether they had any other long term illness, health problem or disability, in addition to IBD. Wording of this item was taken from a question included in the UK Census 2001.

Difficulties with parenting tasks

Difficulties with parenting tasks were assessed using the Parenting Tasks Index (PTI) (Nehring and Cohen, 1995), an instrument designed to assess parenting tasks that are affected by a chronic illness or disability. There are three sections to the Index: Infancy (0-1 years), Childhood (1-10 years), and Adolescence (11-21years). Respondents complete the sections that correspond to the age of their child at the time of the survey. Response items are scaled from 0 to 3: 'no difficulty and requiring no effort' to 'severe difficulty and requiring great effort'. There are 38 items on the Infant PTI scale (scores range from 0 to 114), 40 items on the Child PTI scale (scores range form 0 to 120), and 32 items on the Adolescent PTI scale (scores range from 0 to 96). The content validity of the instrument was established through reference to literature on child development and the impact of parental illness, consultation with an expert group, and a pilot study involving mothers with narcolepsy. The test-retest reliability of the measure was assessed on the pilot sample after a three month interval. Correlations varied between 0.62 and 0.88. The

internal consistency of the measure was measured by calculating Cronbach's Alpha for the association between individual items and all other items in the scale, and ranged between 0.93 and 0.96.

For the purposes of this study, a number of modifications were made to the scale. First, the scale is not explicit about the time period parents are expected to report on. In the survey, parents were asked to report on experiences over the last year. Secondly, the language was anglicised. Thirdly, as parents in the UK are unlikely to be involved in teaching children aged 11-16 to drive, the item on the adolescent scale that refers to this task was not included. Fourthly, since the scale was developed for mothers, pilot work was undertaken to assess the appropriateness of the scale for fathers. Following this work, instructions were added to the instrument indicating that respondents can tick 'not applicable' to any activities they are not responsible for.

Parent's psychological distress

The Hospital Anxiety and Depression Scale (HADS) was used to assess parents' psychological distress. The HADS is a measure of present mood, with respondents asked to respond in relation to how they have been feeling over the previous week. The HADS distinguishes between anxiety and depression, with responses scored on two sub-scales. Items on the scale are scored from 0 to 3, with the total score on each sub-scale ranging from 0 to 21. Questions have been raised as to whether the two subscales measure different aspects of mood, but tests of discriminate and concurrent validity suggest they do, with the subscales differing in clinically meaningful ways as assessed by correspondence with other measures of anxiety and depression (Herrmann, 1997).

One of the main reasons for selecting the HADS for use in this study was that it is designed for people affected by physical illness, with any items that might relate to physical disorder omitted. Furthermore, it is brief, consisting of only 14 items. Evidence of acceptability to respondents was demonstrated in a study involving face-to-face administration of the test to patients involved in a Cancer Research Campaign Conservation Trial (Fallowfield *et al.*, 1987). The HADS has been administered to a wide range of patient groups, including those with IBD, and many studies report high response rates in well motivated samples, sometimes reaching 100 per cent (Herrmann, 1997).

The scale was originally validated on a sample of 100 medical outpatients and hospital staff aged between 16 and 65 years (Zigmond and Snaith, 1983), comparing scores on the test with those made by researchers through a standardised interview. Further testing

of the scale has demonstrated that it is better than the General Health Questionnaire (GHQ) at identifying cases against the criterion of DSM-III psychiatric classification (Wilkinson and Barcazk, 1988), and is equivalent to the 12-item GHQ in detecting cases of minor psychiatric disorder (Lewis and Wessley, 1990). It also compares favourably with the Beck Depression Inventory and the State Trait Anxiety Scale (Herrmann, 1997). There is extensive evidence of ability to distinguish between populations with known differences in anxiety and depression (construct validity), and some studies provide evidence of ability to reflect changes in the criterion variable as a result of interventions (treatment validation) (Herrmann, 1997).

The scale also has acceptable levels on internal consistency. Correlations between each anxiety item and the remaining items in the sub-scale range from 0.80 to 0.93. On the depression scale, item correlations range between 0.81 and 0.90. Test-retest reliability shows a high correlation up to 2 weeks ($r>.80$), with decreases over longer time periods, as might be expected for a measure of prolonged state which aims to be responsive to changes that occur during the course of an illness (Herrmann, 1997).

The HADS was originally designed as a screening instrument and, by converting scores to case level, it can be used to indicate whether an individual is likely to have psychiatric difficulties. Although the sensitivity and specificity of the HADS for detecting caseness are good (on average 0.80 or higher) (Herrmann, 1997), the scale performs badly when used to identify people with a diagnosis of major depression (Silverstone, 1994), and should therefore not be used to make a specific diagnosis (Herrmann, 1997). There is no single generally accepted cut-off score for determining whether or not an individual has case level difficulties. Snaith and Zigmond (1994), the test authors, recommend that HADS scores of between 8 and 10 identify mild cases, 11-15 moderate cases, and 16 or above indicate severe cases of either anxiety or depression. However, Crawford *et al.* (2001) has suggested using a cut-off of 10/11 to identify cases so as to avoid substantial proportions of non-clinical samples obtaining scores outside the normal range, and to produce results broadly consistent with those found when well-validated classification systems are employed. Most researchers have chosen to use one of Snaith and Zigmond's lower two cut offs (Herrmann, 1997). In this survey, the proportion meeting Snaith and Zigmond's criteria for mild, moderate, and severe caseness will be reported in order to allow comparison with other studies.

Support with parenting

The Family Support Scale (Dunst *et al.*, 1988) is a measure designed specifically to assess the helpfulness of sources of support to families, over the previous three to six months, in relation to rearing a young child. The scale includes 18 items, rated on a five-point scale ranging from 'Not at all helpful' (1) to 'Extremely helpful' (5). Respondents are also given the opportunity to state a source of support is not available to them and to list other sources of support. Thus total scores range between 0 and 100. The reliability and validity of the scale were examined in a study of 139 parents of preschool children who were 'handicapped or developmentally at risk'. The coefficient alpha computed from the average correlation among the items was 0.77. The test-retest reliability for the average correlation among the 18 items, produced by administering the scale one month apart, was r=. 75 (SD=. 17, $p<.001$). For the total scale scores it was r=. 91 ($p<0.01$) (Dunst *et al.*, 1988). Principal components factor analysis has yielded a six-factor structure (informal kinship items, social organization items, formal kinship scale, immediate family, specialized professional services, and generic professional services items) (Dunst *et al.*, 1988). The criterion validity of the scale has been established in a number of studies, with the total scale score consistently related to a number of parent and child outcomes, including personal well being, the integrity of the family unit, and parent perceptions of the child's behaviour (Dunst *et al.*, 1988).

For the purposes of this study, the wording of the scale was anglicised. Since the scale was developed for use with parents of children with disabilities, it includes some items unlikely to be relevant to many of the parents involved in this study. Items removed from the scale were 'Support from early childhood intervention program', 'Professional helpers (social workers, therapists, teachers etc)' and 'Professional agencies (public health, social services, mental health, etc). These were replaced with alternatives more appropriate to the parents involved in this study - 'Health visitors', 'Hospital based health professionals (hospital doctors and nurses)' and 'Social service staff'.

Parent's met and unmet service support needs

Support needs have been defined as 'an individual's judgement of the discrepancy between actual states or conditions and what is considered normative, desired, or valued from a help seeker's and not a help giver's perspective' (Dunst *et al.*, 1988:13). Based on the findings from Study 1 (the qualitative research with parents), a checklist was developed to assess parents' met and unmet support needs. It consists of 23 items and follows a similar format to previous surveys of parents met and unmet needs (Beresford, 1995; Sexton *et al.*, 1992). The items cover instrumental help with parenting and

household tasks, dealing with illness/medical emergencies, financial resources, access to suitable housing and parking, medical treatment, information and advice, psychological support, support for partners, and opportunities for the family to meet others in similar circumstances. For each item, parents are asked to state whether they 'Need help but are getting enough', 'Need more help', or 'Help not needed'.

Partner's health

Respondents were asked whether their partner had any long term illness, health problem or disability, which limited his/her daily activities or the work s/he can do.

Child's health

An item was included in the parent survey, asking whether children aged 4-16 years had any long term illness, health problems or disabilities which limits his/her daily activities.

Division of domestic labour within the household

Respondents living with a partner were asked five questions, taken from the British Household Panel Survey (BHPS), about responsibility for household tasks. For each question, a score of 0 is assigned to respondents who report the task is mostly taken care of by their spouse/partner, a score of 0.5 to respondents who share the task with their spouse/partner, and a score of 1 to respondents who are mostly responsible for the task. It is possible to calculate an index of the division of domestic labour by averaging scores across the five questions. For parents with a child under 12 years, the total score is based on the average response to all five items. Parents with children over 12 years do not answer the question on responsibility for care of children, so their score is based on the average response to the remaining four questions. The questions produce results consistent with more precise estimates derived from time diaries (Laurie and Gershuny, 2000).

Socio - demographics

Data on both the parent and their partner's employment status were collected using a single item which asked individuals whether they were working full-time, working part-time, or not employed. Based on a question used in the UK Census 2001, those not employed were given the opportunity to categorise themselves as 'Looking after home/family', 'Retired', 'Long term sick/disabled', 'Student' or 'None of the above'.

Household socio-economic status was assessed using the National Statistics Socio-Economic Classification (NS-SEC). The Office of National Statistics introduced this

classification system in 2001 to replace Social Class based on Occupation (SC) and Socio-Economic Groups (SEG). It is a nested classification system, which can be collapsed into eight, five or three category variables. In this survey, the self-completion version of NS-SEC was used since it is less time consuming and costly to administer. This version produces a five category variable. Comparisons of the self-coded and interviewer coded versions found agreement in coding 75 per cent of cases. Validation exercises show that the self-coded and interviewer-coded five-class NS-SEC display similar patterns and strength in their relationships with other variables (http://www.statistics.gov.uk/methods_quality/ns-sec). In this study, in households where there were two parents, the parent who was the main source of income determined which parent best defined the household position. In cases where the income were equal, the parent with the higher NS- SEC defined the household status.

Parents' educational qualifications were categorised using a system adopted by the Office of National Statistics and used in the UK National Census 2000. This system has seven response categories, some of which are equivalent or highly similar. In order to create a hierarchy of qualifications, categories 3-6 were collapsed, producing a four category scheme ('Degree or degree equivalent and above', 'Other higher education below degree level', 'A level, vocational level 3 and equivalent', and 'No educational or vocational qualifications').

Parents' perception of their financial situation was assessed using a single item taken from the BHPS, which asks individuals how they feel they are managing, with responses rated on a five point scale, ranging from 'Living comfortably' to 'Finding it very difficult'. This is a quick and effective method of accessing information as to whether parents' financial situation is a resource that can be used to cope with other stresses in their life or, alternatively, a source of stress.

Ethnic group was classified according to the system currently adopted by Office of National Statistics. This allows ethnic group to be classified at two levels. Level 1 is a coarse classification into five main ethnic groups. Level 2 nests within Level 1, and provides a finer classification. Since the purpose of recording ethnicity in this study is solely to provide a profile of the sample, Level 1 data were collected (White, Mixed, Asian or Asian British, Black or Black British, Chinese or other ethnic group). (http://www.statistics.gov.uk/about/Classifications/ns_ethnic_classification.asp.

9.9.2 *Child-completed measures*

Communication about IBD

Children were asked a single question on how much they had talked to their parent about the illness prior to taking part in the survey. Responses were rated on a three point scale, from 'Never talked about it' to 'Talked a lot'.

Child's perception of illness severity

Children were asked a single question on how serious they felt their parent's illness was, with responses rated on a four point scale, from 'Not at all serious' to 'Very serious'.

Child's responsibility within the home

The extent to which a child took on responsibility within the home for domestic tasks and caring for others was addressed in three ways. First, based on data from the qualitative interviews with children about ways in which children seek to help their parent with IBD, a 10 item checklist was developed to investigate young people's involvement in domestic tasks and caring for family members. For each item, young people responded on a four point scale, ranging from 'Never did this' to 'Did this all the time'. At the end of the checklist, young people were given the opportunity to list other things they did to help that were not covered by the checklist. Secondly, children were asked how much time per week they spend on chores using a question included in the 1994 wave of the BHPS. Responses were on a five point scale, ranging from 'None or almost none' to 'Six hours or more per week'. Finally, young people's perception of how much they did around the house to help compared to their peers was assessed using a single item, with three response options – 'Less than others', 'About the same as others', or 'More than others'.

Child's involvement in social activities

Children's involvement in social activities with peers was measured using four questions taken from a large-scale survey of the mental health of children and adolescents in Great Britain (Meltzer, *et al.*, 2000). Three of the questions addressed how much time the child spends with friends in different settings, with responses rated on a four-point scale, from 'All your free time' to 'No time'. The fourth question asked whether the young person was involved in organised activities for people their own age within the last year. A total social activity score was created based on responses to the four questions. On the first three questions, individuals were assigned a score between 0-3 (0= not at all and 3 = all of the time). On question four, those who responded 'yes' were given a score of 1 and those

who responded 'no' a score of 0. Responses to the four questions were then summed to create a scale from 0 to 10, with 10 being the highest level of social activity.

School absence due to parent's illness

Young people were asked if they had missed any school days over the past year because of their parent's illness. If they had, they were asked how many school days they had missed, with four response options, ranging from '1-2 days' to 'More than 10 days'.

Child's perception of family relationships

Four questions, taken from the BHPS, were used to assess family relationships. Two ask about the extent to which children talk to parents about issues that matter to them, two about the extent to which children quarrel with parents. Each item was rated on a four point scale, from 'Most days' to 'Hardly ever'.

Child's met and unmet support needs

Based on the findings from the qualitative research with parents and children, four questions were included on support needs. These focus on children's need for information about their parent's health, having someone to talk to about how s/he feels about Mum/Dad's health, opportunities to meet with other young people who have a parent with IBD, and assistance with domestic tasks. The format of the checklist was similar to that used to assess parent's met and unmet support needs, with respondents given three response options: 'Would like this', 'Do not want this', and 'Already have this'.

9.9.3 Measures completed by both parent and child

Child's psychological adjustment

Both the parent-report and self-report version of the Extended Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1999) were used to assess the psychological adjustment of children. Parents were asked to complete a questionnaire for every child within the family aged between 4 and 16 years of age. The self-report version was sent to all children in a family aged between 11 and 16.

The SDQ is a 25 item questionnaire, which generates scores for conduct problems, hyperactivity-inattention, emotional symptoms, peer problems, and prosocial behaviour, each scored on a scale from 0 to 10. Scores on the first four scales can also be summed together to produce a total difficulties score (scored 0-40) The extended version of the questionnaire provides an 'impact score', based on responses to five items which ask

about the distress and social impact of any difficulties experienced. Impact is scored on a scale from 0-10.

In addition to producing symptom and impact scores, data can be converted to case level. Impact caseness has been found to be significantly superior to symptom caseness as a predictor of clinical status, whether according to parent, teacher or self-ratings (Goodman, 1999). Goodman suggests probable cut offs (impact score of one or more) are appropriate when studying a high-risk sample where false positives are not a major concern, but 'definite' cut offs (impact score of 2 or more) should be used in low risk samples where it is important to reduce false positives.

There were a number of reasons for choosing the SDQ. First, it is one of the few measures to assess positive behaviour, in the form of prosocial behaviour, rather than simply focusing on children's deficits, thus making the scale user friendly. Furthermore, measuring prosocial behaviour is important in this study given that the qualitative research with parents suggested this group of children might display more prosocial behaviour than their peers. Other advantages to using the SDQ are that it is brief, consisting of 25 items; it has been developed in the UK, so the wording is appropriate for the population involved in the study; it has recently been used in a large scale survey of young people in Great Britain, providing normative data for 5-15 year olds (Meltzer *et al.*, 2000), and mothers of low-risk children are twice as likely to prefer the SDQ to other measures of children's adjustment (The Child Behaviour Checklist) (Goodman and Scott, 1999).

The reliability and validity of the SDQ is now well-documented, and indicates that it is a useful brief measure of the adjustment and psychopathology of children and youth. The validity of the parent version of the scale was initially demonstrated through a small scale study comparing it to the Rutter questionnaire (Goodman, 1997), and another comparing it with the Child Behaviour Checklist (CBCL) (Goodman and Scott, 1999). Initial pilot work on the self-report version found that it discriminated satisfactorily between community and Child and Adolescent Mental Clinic Samples (Goodman *et al.*, 1998). Preliminary work on validating the extended version of the SDQ was undertaken with a community sample of 467 5 –15 year olds, and a sample of 232 children and teenagers drawn from three child and adolescent mental health clinics (Goodman, 1999).

More recently, the psychometric properties of the SDQ were confirmed and extended in a nationwide epidemiological study of 10,438 British 5-15 year olds, in which SDQ scores were obtained from 96% of parents, 70% of teachers and 91% of 11-15 years (Goodman,

2001). Findings confirmed the predicted five-factor structure. Reliability was generally satisfactory, whether judged by internal consistency (mean Cronbach's alpha=0.73), cross-informant correlation (mean= 0.34), or retest stability after 4-6 months (mean= 0.62). Validity was assessed by examining associations between SDQ scores and DSM-IV diagnosis. SDQ scores above the 90th percentile predicted a substantially raised probability of DSM-IV diagnosed psychiatric disorders (mean odds ratio: 15.7 for parent scales, 15.2 for teacher scales, 6.2 for youth scales). Within the community sample, the proportion of true negatives was high (around 95%) but the proportion of true positives was low (around 35%), as might be expected in a screening questionnaire.

The screening properties of the questionnaire are improved when data from multiple informants is used and a computerised algorithm has been produced to predict psychiatric disorder by bringing together SDQ scores from all informants–parents, teachers, and young people (Goodman *et al.*, 2000). Unfortunately it is not possible to use the algorithm in this study since, due to the limited resources available for the research, teacher-reported SDQ data were not collected. However, lack of teacher reported data is not of great concern when it is considered that parent and teacher data is of roughly equal predictive value (Goodman *et al.*, 2000). In relation to the relative value of parent and self-reported data, it is worth noting that Goodman recommends that while the self-report version can be used to examine group differences, and to understand children's self-perception, it should not be used to make a diagnosis on individuals (Goodman *et al.*, 1998). In the initial pilot work many clinic attendees had self-report scores in the normal/borderline range when their parents or teacher reported a high level of symptoms.

9.10 Data Analysis

There were two main parts to the data analysis. First, a description of parents and young people's experiences and support needs is provided. Second, the conceptual models describing factors hypothesised to moderate and mediate parents' psychological distress and children's emotional and behavioural well-being were tested. Before carrying out this work, data preparation was undertaken. The steps involved in each phase are described below.

9.10.1 Data preparation

Before beginning any work on analysis, data screening was carried out. The distribution of interval level variables, and ordinal variables with at least a five point scale, were

explored to see if they were normally distributed, and might be analysed using a parametric test. Decisions were made through a combination of exploring the data graphically, and through summary statistics, adopting guidelines suggested by Miles and Shevlin (2001). Where there was concern about the distribution of variables, an attempt was made to improve skewed distributions using transformations recommended by Norman and Streiner (2000). In addition, boxplots were produced in order to identify outliers. Outliers due to data entry errors were corrected and plausible scores were retained. Care was taken to check whether the same subject produced outliers on various variables, suggesting that this individual's responses will have disproportionate influence on findings.

Second, given the small numbers of respondents drawn from hospital clinics, it was important to determine whether the voluntary sector and clinic samples could be combined to form a single sample. Therefore, a series of tests were carried out, using Pearson chi-square, the independent sample t-test, and Mann-Whitney U as appropriate, to examine differences between samples on all of the study variables.

9.10.2 Descriptive analysis of data

Having completed the data preparation, the descriptive analysis of all variables collected from parents and children was carried out. Means, standard deviations, confidence intervals, and frequency distributions were calculated as appropriate. Data on the primary outcome measures for parents and children (HADS and SDQ data) were compared against normative data using the one sample t-test and binomial test of proportion.

9.10.3 Testing conceptual models

Finally, regression analysis was used to test conceptual models of factors moderating and mediating parents' psychological distress and children's psychological adjustment.

Model predicting parents' psychological distress

The conceptual model was tested twice: once with parental anxiety as the dependent variable, and once with parental depression as the dependent variable.

Since the HADS symptoms score were normally distributed, it was possible to choose between applying multiple regression analysis to the symptom scores or logistic regression to case level data. While analysis at the case level would provide information

on factors that increase the likelihood of a parent having anxiety and depression sufficiently severe to require intervention, analysis using multiple regression would indicate which factors are related to an increase in symptoms. After some consideration, it was decided that the data should be analysed using multiple regression because it is recommended that investigators never convert interval level data into binary form prior to carrying out multi-variate analysis (Norman and Streiner, 2000). Doing so risks throwing away valuable information about the relationship between variables since it assumes that all those below and above a cut off for caseness are significantly different from each other in relation to the predictor variables. In fact, greater differences on predictor variables may exist elsewhere on the scale. As a result, when the outcome variable is continuous, and the assumptions regarding it and the predictors are met, multiple regression is likely to be more powerful than logistic regression at detecting a relationship between independent and dependent variables (Tabachnick and Fidell, 2001). In addition, it is worth remembering that, in relation to the HADS, there is no agreement regarding the appropriate cut off for caseness.

Regression is most effective when independent variables are strongly correlated with the dependent variable but uncorrelated with other independent variables. Therefore bivariate analysis was used to determine which variables were associated with the dependent variables and should be considered for inclusion in the analysis. Pearson's *r* was used to examine associations with ratio, interval, and binary data. Associations with ordinal level data were examined using Spearman's rho. Categorical data were examined using the independent samples t-test or Anova. Relationships between independent variables and dependent variables significant at the 5 per cent probability level were selected for inclusion in the regression analysis.

Next, associations between the selected independent variables were explored for signs of collinearity. A correlation matrix was produced for ratio, interval, normally distributed ordinal data, and binary data. Categorical data were explored using chi-square analysis and Anova.

In deciding whether to exclude variables due to collinearity, consideration was given to Tabachnick and Fidell's (2001) recommendation that a variable must be removed from the analysis when bivariate correlations of 0.90 or higher are found, and that researchers take care when including variables with a bivariate correlation of 0.70 or more.

Having decided on variables to be included in the regression analysis, variables were entered into the equation in a hierarchical fashion, based on the conceptual model being tested. This meant testing health, and other parent variables, after controlling for socio-demographic variables.

Next, the hypothesized mediating role of parenting difficulty was tested using steps recommended by Baron and Kenny (1986). In order to demonstrate a mediating relationship it was necessary to do the following:

- Show that parental illness is a significant predictor of the dependant variable.
- Show that parental illness is a significant predictor of the hypothesised mediator.
- Show that the hypothesized mediator is a significant predictor of the dependent variable, after controlling for parental illness.

If the hypothesised mediator is a complete mediator of the relationship between parental illness and the dependent variable, the effect of parental illness when controlling for hypothesised mediator should be zero. If it is only a partial mediator, the effect will merely be reduced, not eliminated. This is tested by examining the slope coefficient for illness, when the hypothesised mediator is included in the equation. The degree of mediation can be calculated by comparing the slope coefficient from the joint regression equation with that obtained for parental illness on its own.

Finally, the data were tested for moderators. Testing for moderators involved creating a new variable representing the interaction between the independent variable and its hypothesized moderator. Hierarchical regression analysis was then used to test if the interaction term made a significant contribution to explaining the variance in the dependent variable, over and above that explained by the independent variables individually.

Model predicting children's emotional and behavioural difficulties

Two different measures of young people's emotional and behavioural difficulties were available from the survey: SDQ total difficulties symptom scores and impact scores. An analysis based on symptom scores provides information on factors likely to increase emotional and behavioural symptoms, whereas an analysis based on caseness indicates factors that increase the likelihood of a child having difficulties that are severe enough to require intervention.

As total difficulties scores were normally distributed, it was possible to analyse this data using multiple regression. Impact scores were not normally distributed and were therefore analysed by converting them to case level and applying logistic regression. When converting impact scores to case level, it was decided that both probable and definite cases would be included in the analysis in order not to ignore young people who are experiencing less severe difficulties, and who might benefit from some form of support.

For both multiple and logistic regression, one child per family was selected at random for inclusion in the analysis. The purpose in doing so was to avoid autocorrelation within the data (where lack of independence between cases leads to correlation between residuals). Autocorrelation is a violation of one of the assumptions of multiple regression and can result in regression analysis producing inaccurate lines of best fit (Miles and Shevlin, 2001).

When carrying out the analyses based on multiple regression, the steps taken were the same as described previously in relation to parents' psychological distress.

When carrying out the logistic regression, bivariate analysis was carried out first to determine which variables to enter in to the equation. On this occasion, Mann Whitney U and chi-square analysis were used to test for significant differences in independent variables according to caseness. Independent variables significantly different at the 5 per cent probability level were selected for inclusion in the regression analysis. Next, associations between the selected independent variables were explored for signs of multi-collinearity. Again, a correlation matrix was produced for ratio, interval, normally distributed ordinal data, and binary data. Categorical data were explored using chi-square analysis and Anova.

Having decided on variables to be included in the regression analysis, variables were entered into the equation in a hierarchical fashion based on the conceptual model, after controlling for socio-demographic variables. Once the main effects were tested, the data were examined for evidence of mediation and moderation following the same procedures adopted in the linear regression analysis.

Results of the different elements of the analyses are reported in the following chapters. Chapter 10 deals with the descriptive analysis of the data on parents, Chapter 11 with the descriptive analysis of the data on children, and Chapter 12 with the testing of the conceptual models.

CHAPTER 10

Outcomes for Parents

10.1 Introduction

This chapter presents findings on the experiences and support needs of parents, based on descriptive analysis of data from the survey of parents. This includes findings on parents' psychological distress, difficulties with parenting tasks, the support they receive from others in bringing up their children, and their support needs. To put these findings in context, the chapter opens by reporting on the survey response rate, preliminary work on the data, and the background of survey respondents, including their health, family circumstances, and socio-demographic characteristics.

10.2 Survey Response Rate

Parents were recruited from two sources – hospital gastroenterology clinics and NACC. The response rate across the whole sample, and within these two sources, is summarised in Table 13.

Table 13: Study 3 - Response rate

Source	Number sent screening questionnaire	Response to screening questionnaire	Number eligible for survey	Response to parent's questionnaire
	Count	Count (%)	Count	Count (%)
Hospital clinic				
A	70	39 (55.7)	12	12 (100)
B	114	73 (64.0)	15	13 (86.7)
C	68	48 (70.6)	17	14 (82.3)
D	126	59 (46.8)	18	14 (77.8)
Sub-total	378	219 (57.9)	63	53 (84.1)
NACC	140	135 (96.4)	129	125 (96.9)
Total	518	354 (68.3)	191	178 (92.7)

In relation to the hospital clinics, a total of 378 patients were sent a screening questionnaire and information leaflet inviting them to participate in the study. Within clinics, between 46.8 and 70.6 per cent of patients returned a completed questionnaire, resulting in the identification of 63 parents who were eligible for the study.

In relation to NACC, 140 people responded to the advert placed in the June 2002 edition of the NACC Newsletter and were sent a screening questionnaire. Out of these 140 people, 96.4 per cent returned a completed questionnaire, resulting in the identification of 129 people who met the study inclusion criteria.

The 191 parents who were eligible for the study were then sent the survey questionnaire. The response to the survey was good. Across sources, between 77.8 and 100 per cent of parents completed the survey questionnaire. This resulted in the final sample of 178 parents, which is more than sufficient for the descriptive elements of the analysis.

The effect of non-response to the survey questionnaire was assessed by comparing responders and non-responders on data obtained from the screening questionnaire. Results indicated there was a significant difference in diagnosis (χ^2 =8.298, df=1, p=.004), with cell counts suggesting that non-response was associated with having UC. There was no significant difference in parent's age (t=0.749, df = 12.642, p=.467, 95% confidence interval from –4.274 to 8.794), or in the total number of children the parent had (z=-1.666, p=.096). It was not possible to test for differences in relation to parent's sex, whether they had an ileostomy, length of diagnosis, or whether they were recruited through hospital clinics or NACC, due to low expected cell counts.

10.3 Preliminary Work On The Data

Preliminary work, prior to undertaking the analysis, included the exploration and transformation of variables, comparison of NACC and clinic samples, and the analysis of missing data. This is described in further detail below.

10.3.1 Transformation of variables

After examining data using histograms, and skew and kurtosis ratings (see Appendix 28), it was apparent that fifteen variables were not normally distributed. Each of these variables was transformed to see if this improved the distribution of the data, making it possible to apply parametric tests. The log transformation succeeded in improving the distribution of two variables: the average standardised PTI score and how many years the respondent had been experiencing symptoms of IBD. The remaining 13 variables were not improved by transformation and were therefore treated as ordinal level data (see Appendix 29).

10.3.2 Comparison of NACC and clinic samples

In order to obtain a reasonable sample size, it was necessary to combine clinic and NACC samples. To determine whether it was appropriate to do so, parents recruited through NACC and those recruited through hospital clinics were compared to see if they differed in any way (see Appendix 30 for full results). Out of the 65 variables produced by the parents' survey, significant differences/associations were found in relation to just twelve variables, six of which were items from the checklist of support needs.

Significant variables included whether the respondent's partner had a long term illness, health problem or disability (χ^2 =6.171;df=1;p=0.013), frequency of attending hospital outpatient clinics (z=-3.288, p=0.001), diagnosis (χ^2 =4.709;df =1, p= 0.030), and the child PTI scale scores (z=-2.413, p=0.016). In relation to support needs associations were found between where parents were recruited from and having an opportunity to talk to a counsellor (7.175, df=1, p =.007), an opportunity to talk to other parents with IBD (χ^2 = 5.269, df=1, p=.022), someone to look after child when parent has hospital appointment (χ^2 =4.865, df=1, p=.027), information and advice on IBD for partner (χ^2 =7.111, df=1, p=.008), someone for partner to talk to about respondent having IBD (χ^2 =5.440, df=1, p=.020) and an opportunity for the family to meet other families in a similar situation (χ^2 =6.255, df= 1, p=.012).

Further examination of the data revealed that respondents from NACC were more likely than those recruited through clinics to describe their partner as having an illness/health problem or disability (21.2% versus 4.7%). Respondents recruited through hospital clinics attended hospital outpatient clinics more frequently than those from NACC (mean rank of clinic patients = 102.51, mean rank for NACC sample = 77.22). In relation to participant's diagnosis, a higher percentage of clinic patients had CD (72.0%) than in the voluntary sector (54.1%). On the child PTI score, parents from NACC reported greater difficulty than those recruited through clinics, but the differences were not substantive (NACC median score for clinic samples was 16 compared to 22 for the NACC sample, with scores ranging from 0 to 86). For all types of support, a larger proportion of parents recruited through NACC needed support than did parents recruited through hospital clinics (see Appendix 30, Table 2).

Given that the NACC and clinic sample differed on only a small number of variables which were not the primary outcome measures, and that differences on the Child PTI score were not substantive, it was decided that the samples could be combined.

10.3.3 Missing data analysis

There were missing data on a number of variables. In most cases this was not of great concern, consisting of less than 5 per cent of the total sample (Norman and Streiner, 2000). However, there were two variables with missing data from more than 5 per cent of the sample: PTI scores and Family Support. In relation to PTI data first, 19.63% (21/107) of parents did not respond to item 36 of the childhood PTI scale because of a typing error in the first batch of questionnaires mailed out (the response options were not printed on the checklist). As a result, it was decided that responses to this item would excluded from the analysis. This meant that scores on the child PTI scale ranged from 0 to 117 and the adolescent PTI scale from 0 to 93. Despite this amendment, when the average PTI scores was calculated, data were missing from 14.61% (26/178) of the sample. It seems likely that missing data are simply due to the scales being lengthy, increasing the likelihood that people will miss an item.

In relation to the Family Support scores, 10.67% (19/178) of scores were missing. Again, it seems likely that this is due to the scale being lengthy. These missing data were dealt with by using pairwise deletion of data during the analysis.

10.4 Characteristics Of Participants

Respondents were predominantly female (80.3%, 142/178), and ranged between 23.2 and 65.5 years, with a mean age of 38.5 years (95% confidence interval for the mean from 37.54 to 39.45). They had experienced symptoms of IBD for between 1 and 35 years, with a median of 10 years. The most common form of IBD was CD (57.3%), followed by UC (39.3%). A few respondents described themselves as having IBD, or CD and UC, and some specified that they had Crohn's colitis or microscopic colitis. A breakdown of parents' diagnosis is given in Table 14.

Table 14: Study 3 – Respondents' diagnosis

Diagnosis	Number of parents (%)
Crohn's Disease (CD)	102 (57.3)
Ulcerative colitis (UC)	70 (39.3)
UC and CD	2 (1.1)
Crohn's colitis	2 (1.1)
Inflammatory bowel disease (IBD)	1 (0.6)
Microscopic colitis	1 (0.6)

Table 15 provides a summary of the respondents' medical treatment for IBD. During their lifetime, the majority had stayed overnight in hospital due to IBD and just under half had been through surgery. Within the previous year, almost all respondents had attended an outpatient clinic. In addition, 27.1% had stayed overnight in hospital, and 12.9 % had been through surgery, due to the condition. The vast majority were prescribed regular medication. For 54.8% this included steroids, and 40.3% were prescribed immunosuppressants. Just 5.6 % of parents had a permanent ileostomy, ileoanal pouch or colostomy and 3.4% had a temporary ileostomy or colostomy.

Table 15: Study 3 – Respondents' medical treatment for IBD

During your lifetime have you....	Number of parents (%)
stayed overnight in hospital	136/177 (76.8)
been through surgery	82/175 (46.9)
During the past year have you.....	
attended an outpatient clinics	168/177 (94.9)
stayed overnight in hospital	48/177 (27.1)
been through surgery	23/176 (12.9)
been prescribed regular medication	158/176 (89.8))
been prescribed steroids	97/177 (54.8)
been prescribed immunosuppressants	71/176 (40.3)
Do you have a	
permanent ileostomy, ileoanal pouch or colostomy	10/177 (5.6)
temporary ileostomy, ileoanal pouch or colostomy	6/177 (3.4)

Scores on a measure of IBD-related health status and quality of life – the SIBDQ, varied between 1 and 7 (1 indicating poor health and 7 being optimum health), with a mean of 4.37, standard deviation 1.25 (95% confidence interval from 4.18 to 4.56).

In order to compare the SIBDQ data with data from other studies, scores for CD and UC patients were examined separately. In the study sample, SIBDQ scores for CD patients ranged between 1.80 and 7.00, with a mean of 4.20, standard deviation 1.22 (95% confidence interval ranging between 3.95 and 4.45). Scores for UC patients ranged between 1.20 and 6.90, with a mean of 4.64 and a standard deviation of 1.29 (95%

confidence interval from 4.33 to 4.95). An independent sample t- test revealed a significant difference between CD and UC patients (t=-2.235, df= 163, *p*=.027, 95% confidence interval of the difference ranging between -.83 and -.05), indicating that patients with UC perceived themselves as having significantly better health status and quality of life than patients with CD. These scores were similar to that obtained by Irvine *et al.'s* (1996) work with patients with *active* CD and UC: CD patients recruited from 14 gastroenterology clinics, who had stable but active disease, were found to have mean SIBDQ scores ranging between 4.00 and 4.92, whereas patients in remission had mean score ranging between 4.67 and 5.83. Patients with UC were recruited from just one clinic. Those with active disease had mean scores of 4.79 +/- 1.17, compared to 5.90 +/- 0.80 (*p*=0.006) for those in remission.

In addition to IBD, 32.2 % (57/177) of respondents said they had another long term illness, health problem or disability which limited their daily activity or the work they could do. These included a wide range of physical illnesses and disabilities (eg., arthritis, diabetes, epilepsy, MS, psoriasis), as well as some mental health problems (e.g. agoraphobia, bulimia, depression).

Almost all respondents described themselves as 'White' (96.6%, 172/178). They were drawn largely from households classified as representing managerial and professional occupations (57.1%), though all other socio-economic classifications were represented (see Table 16).

Table 16: Study 3 - Household socio-economic classification

Classification	Count	(%)
Managerial and professional occupations	100	(57.1)
Lower supervisory and technical occupations	25	(14.3)
Semi-routine and routine occupations	22	(12.6)
Small employers and own account managers	15	(8.6)
Intermediate occupations	13	(7.4)
Total	175	100)

Most had qualifications up to or equivalent to A level or Vocational level 3 (see Table 17) and were employed at the time of the survey (37.1% working part-time; 25.8 % working full-time). Perceptions of how they were managing financially ranged from 'living comfortably' to 'finding it very difficult', with most saying they were 'doing alright' (30.5%, 54/177) or 'just about getting by' (28.8%; 51/177). Just 6.2% (11/177) were 'finding it very difficult'.

Table 17: Study 3 - Respondents' highest level qualification

	Highest level qualification	Count (%)
1	*Degree or degree equivalent & above* e.g. MA, PhD, PGCE, postgraduate certificates/diploma, BA, BSc	34 (19.3)
2	*Other higher education below degree level* Qualified Nurse, midwife, health visitor, NVQ levels 4-5, HNC,HND	13 (7.4)
3	*Qualifications up to A-level, vocational level 3 &* equivalent A levels, AS levels, Higher School Certificate, O-levels/CSEs, GCSEs (grades A-C), School certificate, NVQ Level 1-2, Foundation – Advanced GNVQ, City & Guilds, RSA/OCR,BTEC/Edexcel	120 (68.1)
4	*No educational or vocational qualifications*	9 (5.1)

At the time of the survey, respondents had between 1 and 4 children under the age of 16 living at home, with a mean age of 9.38 years (Standard deviation 3.61). The majority of respondents (87.6%,156/178) were living with a partner. In most cases the partner was working (74.8%, 116/155 full-time; 16.1 %, 25/155 part-time) and was the main source of income (67.3%, 103/153). In 16.7% (26/156) of cases the partner had a long-term illness, health problem, or disability, which limited his/her daily activity or the work they could do. In most cases the health problem or disability was physical (eg. arthritis, asthma, CD, MS), but a few parents mentioned mental health problems (e.g. bipolar affective disorder, depression).

On a measure of the extent to which respondents' shared household responsibilities with their partner, scores ranged from 0 to 1.00 (0 indicating that partners were mostly responsible for household tasks, 1 indicating that the respondent was mostly responsible for household tasks), with a median score of 0.75. Females reported significantly greater responsibility for household labour than males (Mann-Whitney U=190.00, $p<0.001$). When individual items that make up the measure of household responsibility were examined separately, the pattern of females taking on more responsibility than men was consistent across all tasks (grocery shopping, cooking, cleaning/hoovering, washing and ironing, care of children under 12 years of age) (see Appendix 31 for results).

10.5 Survey Findings

10.5.1 Difficulties with parenting

Respondents' difficulties with parenting tasks were assessed via the PTI, with parents completing up to three sub-scales, depending on the age of their children. On the infant scale, scores ranged between 0 and 57, with a median of 13. On the child scale, scores ranged between 0 and 86 with a median of 21. On the adolescent scale, scores ranged between 0 and 72, with a median of 16. No differences were found in response to the three scales according to the parent's sex. There was a significant correlation between the age of the youngest child and the log of the parent's average standardised PTI score, indicating that the younger the child the greater the difficulty with parenting. However, the level of association was small ($r=-.56$, $p=.048$).

In order to identify the type of tasks parents had difficulty with, items on sub-scales of the PTI were rank ordered according to the proportion of parents having moderate or severe difficulty with a task (see Tables 18-20). On a positive note, no parents of infants had moderate to severe difficulty picking up or putting down their baby, cuddling/comforting or hugging, talking or listening to the baby, giving medication, helping their baby to talk, drink from cup, or with toilet training. Similarly on the child and adolescent scales, it was rare for a parent to have moderate to severe difficulty with holding, hugging, or comforting their child (6.4% and 3.2% respectively), or with talking/listening to their child (4.0% and 9.5% respectively).

Across age groups, the most problematic tasks were performing household chores (between 46.7 and 50.4% had moderate to severe difficulty across the three sub-scales), and providing for financial needs (between 38.3 and 47.9 % reported moderate to severe difficulty across the three sub-scales). In addition, a range of social activities were also reported as difficult, including going to parent/child classes, going to the zoo/museum, going to the playground, day trips and outings, hosting a birthday party, taking a holiday with the family, playing with the child both outdoors and indoors, visiting extended family, participating in/attending preschool/school events, and allowing the child's friends to visit. Across these tasks, the proportion reporting moderate to severe difficulties varied between 16.7% and 48.9%.

Table 18: Study 3 - Difficulty with infant parenting tasks

Rank	Type of activity	Moderate/ severe difficulty Count (%)
1	Performing household chores	7/15 (46.7)
2	Providing for financial needs	6/15 (40.0)
3	Going to parent/child classes	4/11 (36.4)
4	Going to the zoo, museums with your baby	4/12 (33.3)
5	Disciplining your baby & following through	4/14 (28.6)
6	Going to the playground	3/11 (27.3)
7	Bathing	3/14 (21.4)
8	Visiting extended family (e.g. grandparents) or friends	3/15 (20.0)
9	Shopping for baby's needs	3/15 (20.0)
10	Reading cues for hunger, sleep etc.	3/15 (20.0)
11	Having a friend over to play	2/10 (20.0)
12	Using a baby car seat	3/15 (20.0)
13	Putting up/down crib sides	2/11 (18.2)
14	Taking a holiday with family	2/12 (16.7)
15	Putting child in high chair	2/13 (15.4)
16	Breast or bottle feeding	2/13 (15.4)
17	Taking care of your baby's needs	2/15 (13.3)
18	Feeding solid foods	2/15 (13.3)
19	Playing with your baby	2/15 (13.3)
20	Brushing baby's gums/teeth	1/11 (9.1)
21	Following a nap/sleep routine	1/12 (8.3)
22	Reading books	1/12 (8.3)
23	Scheduling bedtime activities	1/14 (7.1)
24	Changing nappies	1/14 (7.1)
25	Going to doctor/dentist	1/14 (7.1)
26	Helping to walk/crawl	1/14 (7.1)
27	Dressing	1/15 (6.7)
28	Reading cues when sick (e.g. pulling on ears)	1/15 (6.7)
29	Providing transportation	1/15 (6.7)
30	Providing safety measures (e.g. gates, locks etc.)	1/15 (6.7)
31	Picking up your baby	0/15 (0)
32	Putting down your baby	0/15 (0)
33	Cuddling/hugging/comforting	0/15 (0)
34	Giving medication to your baby	0/9 (0)
35	Helping to talk	0/13 (0)
36	Helping your baby to drink from a cup	0/13 (0)
37	Talking/listening to baby	0/15 (0)
38	Help with toilet training	0/15 (0)

Table 19: Study 3 - Difficulty with child parenting tasks

Rank	Type of activity	Moderate/severe difficulty Count	(%)
1	Performing household chores	61/121	(50.4)
2	Providing for financial needs	56/117	(47.9)
3	Caring for more than one child	44/92	(47.8)
4	Hosting a birthday party	55/125	(44.0)
5	Day trips and outings	56/126	(44.4)
6	Taking a holiday with family	47/122	(38.5)
7	Playing with your child outdoors	44/126	(34.9)
8	Visiting extended family (e.g. grandparents) & friends	40/124	(32.3)
9	Participating in/attending preschool/school	35/116	(30.2)
10	Disciplining your child & following through	38/125	(30.4)
11	Allowing child's friends to visit	35/117	(29.9)
12	Providing transportation	32/120	(26.7)
13	Following a sleep routine	31/117	(26.5)
14	Shopping for child's needs	32/123	(26.0)
15	Help with running, skipping, and hopping	25/104	(24.0)
16	Playing with your child indoors	28/126	(22.2)
17	Arranging for a babysitter	23/106	(21.3)
18	Helping to maintain a good sleep routine	25/121	(20.7)
19	Assisting in child's homework	20/106	(18.9)
20	Going to the doctor/dentist	23/123	(18.7)
21	Following a bedtime routine	22/124	(17.7)
22	Helping child develop writing/reading & math skills	21/121	(17.4)
23	Providing meals	20/120	(16.7)
24	Helping to bathe	20/120	(16.7)
25	Taking care of any illnesses/medical needs	20/121	(16.5)
26	Help with learning letters and numbers	13/114	(11.4)
27	Help with feeding	8/99	(8.1)
28	Helping to dress	8/110	(7.3)
29	Reading to child	9/125	(7.2)
30	Selecting a pre-school/school	7/106	(6.6)
31	Holding/hugging/comforting	8/125	(6.4)
32	Helping to brush teeth	7/109	(6.4)
33	Using a car seat/buckle	7/115	(6.1)
34	Help with drinking	5/98	(5.1)
35	Talking/listening to child	5/125	(4.0)
36	Providing health education	3/108	(2.8)
37	Allowing for child's privacy	3/107	(2.8)
38	Help with talking, speaking sentences	3/117	(2.6)
39	Safety issues (e.g. gates, poisons etc.)	4/117	(3.4)

Table 20: Study 3 - Difficulty with adolescent parenting tasks

Rank	Type of activity	Moderate/ severe difficulty Count (%)
1	Hosting parties	22/45 (48.9)
2	Performing household chores	30/62 (48.4)
3	Taking a holiday with family	26/62 (41.9)
4	Participating in/attending school activities with child	25/62 (40.3)
5	Providing transportation	22/57 (38.6)
6	Providing for financial needs	23/60 (38.3)
7	Assigning household chores and enforcing	21/63 (33.3)
8	Visiting extended family (e.g. grandparents) & friends	19/63 (30.2)
9	Shopping for child's needs	18/60 (30.0)
10	Caring for more than one child	14/47 (29.8)
11	Providing meals	17/58 (29.3)
12	Allowing child's friends to visit	15/60 (25.0)
13	Disciplining your child & following through	15/62 (24.2)
14	Going to the doctor/dentist	11/61 (18.0)
15	Helping with clothes selection	9/53 (17.0)
16	Working with child to develop writing, reading & math skills	10/59 (16.9)
17	Planning for life after school	7/44 (15.9)
18	Helping to make choices about school (e.g., selecting school, subjects to study)	9/61 (14.8)
19	Setting a curfew	8/56 (14.3)
20	Helping to maintain a sleep routine	8/59 (13.6)
21	Arranging for a baby sitter	5/38 (13.2)
22	Assisting in child's homework	8/63 (12.7)
23	Taking care of medical needs	7/60 (11.7)
24	Talking/listening to child	6/63 (9.5)
25	Helping to maintain dental hygiene	6/62 (9.7)
26	Talking about dating	3/53 (5.7)
27	Allowing for child's privacy	3/63 (4.8)
28	Hugging/comforting	2/63 (3.2)
29	Safety issues (e.g. gates, poisons etc.)	2/60 (3.3)
30	Providing health education	0/61 (0)
31	Making sure child uses a seat belt	0/54 (0)

10.5.2 Parents' psychological distress

On a standardised measure of anxiety and depression during the past week (HADS), on which scores range between 0-21 (21 indicating maximum levels of anxiety/depression), respondents had a mean anxiety score of 9.06 (SD = 4.38; 95% confidence interval for the mean from 8.41 to 9.71), and a mean depression score of 6.70 (SD= 4.17; 95% confidence interval for the mean ranging between 6.09 and 7.32).

A statistically significant difference was found in anxiety according to sex (t= 1.983;df=174, p=0.049; 95% confidence interval of the difference from 0. 007 to 3.2826),

with females reporting higher anxiety than males (mean scores = 9.38 and 7.73 respectively). There was no difference in depression according to sex (t=0.898, df=176, p=0.370; 95% confidence interval of difference from –0.835 to 2.229). When differences between people diagnosed with UC and CD were tested, a statistically significant difference was found in depression (t= 2.125;df=168, p=0.035; 95% confidence interval of the difference from 0.093 to 2.540), with respondents with CD reporting higher depression than those with UC (mean scores = 7.24 and 5.93 respectively). There was no statistically significant difference in anxiety according to diagnosis (t=1.283, df=168, p=0.201; 95% confidence interval of difference from –0.472 to 2.222).

When scores were converted to case level, results suggested that a substantial proportion of parents were at risk of emotional difficulties severe enough to warrant intervention. Using criteria suggested by the test authors (Snaith and Zigmond, 1994), 60.8% of respondents had case level anxiety, with 23.3% (41/176) classified as mild, 29.0% (51/176) as moderate, and 8.5% (15/176) as severe cases. On the depression scale, 41.6% of respondents reached caseness. In 25.3% (45/178) of respondents depression was mild, in 12.9% (23/178) it was moderate, and 3.4% (6/178) it was severe. As discussed in Chapter 9, Crawford *et al.* (2001) suggested using a more stringent criteria to identify cases. Using Crawford's cut-off, a total of 37.5% (66/176) of respondents had case level anxiety and 16.3% (29/178) had case level depression.

When the proportion of the survey sample identified as being a case on *either* the anxiety or depression sub-scale of the HADS were calculated, 67% had mild to severe psychiatric difficulties (scores >8), and 39.7% met Crawford's criteria for caseness (HADS scores >10).

Table 21 illustrates how parents' HADS scores compare with normative data recently derived from a large non-clinical sample considered to be broadly representative of the general adult UK population in terms of age, gender and occupational status (Crawford *et al.*, 2001). The proportion of cases of anxiety in the study sample (37.5%) is substantially more than in the community sample (12.6%), and the binomial test of proportion confirmed that this difference is statistically significant (p=<0.001). In relation to depression, once again the proportion of cases in the study sample (16.3%) is substantially greater than in the community sample (3.6%), and the binomial test of proportion indicated that this difference is statistically significant (p=<0.001).

Table 21: Study 3 - Comparison between study sample and normative UK data on HADS

	Study Sample N=178	**Normative UK data N=1792**
Anxiety- Snaith & Zigmond's criteria	%	%
Mild case (score 8-10)	23.3	20.6
moderate case (score 11-15)	29.0	10.0
severe case (sore 16 plus)	8.5	2.6
Total cases	60.8	33.2
Anxiety - Crawford's criteria (score 11 plus)	37.5	12.6
Depression-Snaith & Zigmond's criteria	%	%
Mild case (score 8-10)	25.3	7.8
moderate case (score 11-15)	12.9	2.9
severe case (score 16 plus)	3.4	0.7
Total cases	41.6	11.4
Depression-Crawford's criteria (score 11 plus)	16.3	3.6

However, it would be unwise to draw firm conclusions from these comparisons, since the community and study sample differ according to gender. In the community sample there was an almost even distribution of males and females (54.6% female), whereas the study sample is heavily weighted towards females (80.3%). For this reason, a comparison between the study and community sample was made after splitting the data according to sex (see Table 22).

Table 22: Study 3 - Comparison between study sample and normative UK data on HADS with data split according to respondent's sex

	Percentage meeting Crawford's critera for caseness (HADS score 11 plus)	
	Study Sample N=178	**Normative UK data N=1792**
Females	%	%
Anxiety	40.1	26
Depression	18.2	5
Males		
Anxiety	26.5	9
Depression	8.6	3

This comparison revealed that, amongst females, the prevalence of both anxiety and depression are substantially greater in the study sample compared to the community sample. The binomial test of proportion confirmed that these differences were statistically significant (p=<0.001). In relation to males, although the prevalence of anxiety and

depression are greater in the study sample, the binomial test of proportion indicated that these differences were only statistically significant in relation to anxiety (p=0.003).

In recent years a number of studies have been published which report on the results of administering the HADS to IBD patients (see Table 22). The rates of anxiety and depression reported in the survey sample do appear to be greater than reported in other studies of IBD patients attending outpatient clinics (Guthrie *et al.*, 2002; Nordin *et al.*, 2002; Simren *et al.*, 2002; Porcelli *et al.*, 1994; Andrews *et al.*, 1987). Levels of anxiety and depression are also substantially higher than that reported in a recent survey of parents with cancer, in which 38% of parents had mild to severe anxiety and 8% mild to severe depression (Nelson *et al.*, 2002). Unfortunately, in addition to differences between studies in the proportion of males and females within the sample, comparison of the thesis findings with other studies on IBD is complicated by differences in the proportion of respondents with UC and CD.

Table 22: Study 3 - Comparison of HADS data with that reported in other studies of people with IBD

Author	Sample	Proportion of cases		
		Depression	Anxiety	Either scale
Thesis sample	N-=178 CD=102. UC=70, other IBD diagnosis= 6 142 female, 36 male 2ndry & tertiary	25.3% score 8-10 16.3% score >10	23.3% score 8-10 37.5% score >10	67% scores >8 39.7% scores>10
Guthrie *et al.* (2002)	N=116 37 UC, 75CD 64 female, 48 male 2ndry & tertiary outpatient			47.4% score >8 25.9% score >10
Simren *et al.* (2002)	N=83 43 UC, 40 CD 47 female, 36 male In remission	7% score 8-10 2% score >10	14% score 8-10 12% score >10	
Nordin *et al.* (2002)	N=492 331 UC, 161 CD outpatients	9% 8-10 4% >10	14% 8-10 15% >10	
Porcelli *et al.* (1994)	N=150 115 UC, 35 CD 59 female, 91 male outpatients	30.7% >8	52.7% >8	
Andrews *et al.* (1987)	N=162 91 CD, 71 UC 91 female, 71 male outpatients			UC 34% >8 CD 33% >8

10.5.3 Support from others

The extent to which parents received support from others in bringing up their child/children over the past three to six months varied considerably, with scores on the Family Support Scale ranging between 4 and 63, with a mean of 27.75 (SD= 10.30; 95% confidence interval ranging from 26.14 to 29.37).

To examine which sources of support were most helpful to parents, the percentages of total respondents who rated each source as 'very helpful' or 'extremely helpful' were calculated and rank ordered (see Table 22). Parents were most likely to perceive their immediate family as helpful sources of support, with the partner/spouse most frequently named as 'very' or 'extremely helpful' (66.1%), followed by the respondent's parents (40.0%), the respondent's friends (24.0%), spouse or partner's parents (22.4%) and children (20.1%). In relation to statutory services, parents were most likely to consider hospital-based health professionals as helpful sources of support, though only 17.6% rated them as very or extremely helpful, followed by General Practitioners (14.6% rated them as very or extremely helpful). Social services staff received particularly low ratings, with only 1.8 % considering them to have been very or extremely helpful. However, this is explained by the fact that the majority of parents (88.8%) were not in contact with social service staff.

Table 23: Study 3 - Sources of support in bringing up children

Source of Support	**Very/extremely helpful**	**Not available**
	Count (%)	
Spouse or partner	113/171 (66.1)	13/171 (7.6)
My parents	68/ 170 (40.0)	30/170 (17.6)
My friends	41/171 (24.0)	19/171 (11.1)
My spouse or partner's parents	38/170 (22.4)	50.170 (29.4)
My own children	34/169 (20.1)	48/169 (28.4)
My relatives	34/170 (20.0)	34/170 (20.0)
Hospital-based health professionals (hospital doctors, nurses etc.)	30/170 (17.6)	59/170 (34.7)
My family doctor	25/171 (14.6)	31/171 (18.1)
Nursery staff/school teachers	20/167 (12.0)	55/167 (32.9)
My spouse or partner's relatives	17/171 (9.9)	57/171 (33.3)
My spouse or partner's friends	18/69 (10.7)	69/169 (40.8)
Other parents	11/166 (6.6)	76/166 (45.8)
Work colleagues	11/170 (6.5)	87/170 (51.2)
Health visitor	9/169 (5.3)	107/169 (63.3)
Church members/minister	7/169 (4.1)	125/169 (74.0)
Parent groups	8/169 (4.7)	129/169 (76.3)
Social groups/clubs	5/168 (3.0)	130/168 (77.4)
Social service staff	3/169 (1.8)	150/169 (88.8)

Respondents were given the opportunity to name others who were helpful to them in bringing up their children. The list included stoma nurses, child minders, playgroups, counsellors, IBD nurse specialists, neighbours, psychiatrists, paediatricians, and the housing association. Each of these sources of support was described as helpful by just one respondent.

10.5.4 Parents' support needs

Parents completed a checklist on support needs (see Table 24), revealing that a high proportion parents had a need for advice on stress management (72.1%), access to disabled parking (67.4%), information and advice on the effects of IBD on family life (64.3%), more than one toilet in their home (60.5%), a booklet which explained IBD to children (59.9%), advice on explaining IBD to their child (57.6%), an opportunity to talk to a counsellor about coping with IBD (53.8%), and to talk to other parents with IBD (49.4%).

In some cases these needs were met. When parents' *unmet* needs (i.e. 'Need this and not getting it') were examined, more than fifty per cent of respondents had an unmet need for advice on stress management (65.7%), a booklet which explains IBD to children (55.8%), access to disabled parking (55.2%) and advice on explaining IBD to their child (54.1%).

Table 24: Study 3 - Parents' support needs

Type of help needed	Support needed	Support need unmet	Total Count
	Count (%)		
1. Advice on stress management	124 (72.1)	113 (65.7)	172
2. Access to disabled parking to make it easier to get to toilets quickly	116 (67.4)	95 (55.2)	172
3. Information & advice on the effects of IBD on family life	110 (64.3)	81 (47.4)	171
4. More than one toilet in our house	104 (60.5)	62 (36.0)	172
5. A booklet which explains IBD to my child	103 (59.9)	96 (55.8)	172
6. Advice on explaining IBD to my child	99 (57.6)	93 (54.1)	172
7. An opportunity to talk to a counsellor about coping with IBD	91 (53.8)	77 (45.6)	169
8. An opportunity to talk to other parents with IBD	83 (49.4)	65 (38.7)	168
9. Someone to look after my child when I have hospital appointments	78 (45.1)	34 (19.7)	173
10. Financial support to assist with prescriptions	74 (43.3)	52 (30.4)	171
11. My partner needs information & advice on IBD	63 (39.4)	33 (20.6)	160
12. Time to recover from treatment before being sent home from hospital	62 (36.0)	36 (20.9)	172
13. Help with housework	61 (35.7)	41 (24.0)	171
14. Someone to look after my child when I am in hospital overnight	59 (34.1)	17 (9.8)	173
15. Help getting my child to & from school	57 (33.1)	24 (14.0)	172
16. My partner needs someone to talk to about me having IBD	51 (31.9)	38 (23.8)	160
17. Help with shopping	54 (31.2)	30 (17.3)	173
18. My family needs an opportunity to meet other families in a similar situation	46 (27.7)	32 (19.3)	166
19. Help contacting family in times of a medical emergency	41 (24.1)	13 (7.6)	170
20. Help preparing meals	41 (23.7)	22 (12.7)	173
21. Information & advice on ileostomies	39 (22.9)	21 (12.4)	170
22. Information & advice on returning home after surgery	34 (20.0)	21 (12.4)	170
23. Information & advice on the effects of IBD on pregnancy	32 (18.8)	14 (8.2)	170
24. Home treatment for bowel rest & tube feeding so do not have to go into hospital	24 (14.2)	19 (11.2)	169

Chi-square analysis was used to check whether there was an association between parents' support needs and their diagnosis, sex, and the age group of their youngest child (0-4 years, 4-10 years, or 11-16 years) (see Appendix 32). It was not possible to examine whether these factors were associated with *unmet* need because of low expected cell counts.

Results revealed that parent's sex had the greatest influence on parent's support needs, with an association found with 10 out of the 22 support needs. These were whether

parents wanted access to disabled parking, help with explaining IBD to their children, an opportunity to talk to a counsellor, time to recover from treatment before being sent home from hospital, help with housework, someone to look after their child while in hospital for an appointment or staying overnight, and information and advice on pregnancy. In all cases, mothers had a greater need for support than fathers (see Table 25).

There was an association between parent's diagnosis and five types of support: needing advice on explaining IBD to children, time to recover from treatment before being sent home for hospital, help contacting family in times of emergency, someone to look after their children when in hospital overnight, home treatment for bowel rest and tube feeding, and information and advice on returning home for surgery. In all cases, those who needed support were more likely to have CD than UC (See Table 26).

Finally, when chi-square analysis was used to examine how support needs varied according to the age range of the youngest child, significant associations were found in relation to nine types of need: information and advice on the effects of IBD on family life, an opportunity to talk to other parents with IBD, someone to look after my child when I have hospital appointments, time to recover from treatment before being sent home from hospital, help getting my child to and from school, for the family to have an opportunity to meet other families in a similar situation, information and advice on returning home after surgery, and information and advice on the effects of IBD on pregnancy. In most cases, the need for support was greatest with younger children, particularly children under 5 years of age, and tapered off as children reach adolescence (see Table 27). Exceptions were 'time to recover from treatment before returning home from hospital', where the need was greatest amongst those whose youngest child was aged 5-10 years, 'information and advice on returning home from after surgery', where need increased as the age of the youngest child increased, and 'help getting children to and from school', where the need was greatest amongst whose youngest child was aged 5-10 years.

Table 25: Study 3 - Support needs significantly associated with the parent's sex

Type of help needed	Percentage of males and females needing help	χ^2	Df	Sig.
Access to disabled parking to make it easier to get to toilets quickly	Female 72.5 Male 47.1	8.018	1	.005
A booklet which explains IBD to my child	Female 65.2 Male 38.2	8.267	1	.004
Advice on explaining IBD to my child	Female 63.0 Male 35.3	8.599	1	.003
An opportunity to talk to a counsellor about coping with IBD	Female 57.8 Male 38.2	4.174	1	.041
Someone to look after my child when I have hospital appointments	Female 52.5 Male 14.7	15.776	1	<.001
Time to recover from treatment before being sent home from hospital	Female 40.6 Male 17.6	6.223	1	.013
Help with housework	Female 40.1 Male 17.6	6.009	1	.014
Someone to look after my child when I am in hospital overnight	Female 38.1 Male 17.6	5.100	1	.024
Help with shopping	Female 36.0 Male 11.8	7.455	1	.006
Information and advice on the effects of IBD on pregnancy	Female 23.5 Male 0	9.855	1	.002

Table 26: Study 3 - Support needs associated with parent's diagnosis

Type of help needed	Percentage of parents with UC and CD needing help	χ^2	Df	Sig.
Advice on explaining IBD to my child	CD 63.6 UC 47.8	4.114	1	.043
Time to recover from treatment before being sent home from hospital	CD 43.9 UC 22.1	8.407	1	.004
Help contacting family in times of emergency	CD 30.5 UC 14.5	5.669	1	.017
Someone to look after my child when I am in hospital overnight	CD 45.5 UC 17.6	13.865	1	<.001
Home treatment for bowel rest & tube feeding	CD 19.4 UC 7.7	4.257	1	.039
Information & advice on returning home after surgery	CD 26.8 UC 7.5	9.671	1	.002

Table 27: Study 3 - Support needs associated with age group of youngest child

Type of help needed	Percentage of different age group needing help	χ^2	Df	Sig.
Information & advice on the effects of IBD on family life	0-4 yrs 70.9 5-10 yrs 66.1 11-16 yrs 47.2	6.145	2	.046
An opportunity to talk to other parents with IBD	0-4 yrs 60.3 5-10 yrs 43.6 11-16 yrs 34.3	7.607	2	.022
Someone to look after my child when I have hospital appointments	0-4 yrs 58.0 5-10 yrs 39.3 11-16 yrs 25.0	12.104	2	.002
Time to recover from treatment before being sent home from hospital	0-4 yrs 25.0 5-10 yrs 44.6 11-16 yrs 47.2	7.980	2	.018
Help getting my child to & from school	0-4 yrs 32.5 5-10 yrs 44.6 11-16 yrs 16.7	7.768	2	.021
My family needs an opportunity to meet other families in a similar situation	0-4 yrs 38.2 5-10 yrs 23.2 11-16 yrs 11.8	9.022	2	.011
Information & advice on returning home after surgery	0-4 yrs 12.8 5-10 yrs 21.4 11-16 yrs 33.3	6.584	2	.037
Information & advice on the effects of IBD on pregnancy	0-4 yrs 30.8 5-10 yrs 12.5 11-16 yrs 2.8	14.186	2	.001

CHAPTER 11

Outcomes for Children

11.1 Introduction

This chapter presents findings on the experiences and support needs of children who have a parent with IBD. These findings are presented in two parts. First, results from the survey of young people aged 11-16 years are described. This includes young people's perception of their social activity with peers, relationship with parents, responsibilities within the home, school attendance, psychological adjustment, prosocial behaviour, and support needs. Second, results from the survey of parents on their perception of the psychological adjustment and prosocial behaviour of their children aged 4-16 years are presented.

11.2 Part One: Young People's Views

Before reporting the results of the survey of young people aged 11-16 years, the findings are put in context, with a description of the survey response rate, preliminary work on the data prior to undertaking the analysis, and the characteristics and family background of the young people who took part.

11.2.1 Response Rate

A total of 102 young people, drawn from 79 families, were sent a survey questionnaire. In sixty-six cases (64.7%) this was via parents recruited through NACC, in 36 cases (35.3%) via parents recruited through hospital clinics. Seventy-four young people, drawn from 59 families, returned a completed questionnaire. This represents a response rate of 72.5%, of all those who were sent a questionnaire (see Table 28 for a breakdown of response rate according to the different sources of recruitment). However, since the researcher was reliant on the parent passing the survey questionnaire to their child, the number who received the information pack is unknown. It is possible that parents acted as gatekeepers to the survey, and some young people may not have received the questionnaire.

Although the sample size is sufficient for the descriptive analysis of the parent-reported SDQ data (see Chapter 9, section 9.4.2.), it falls slightly short of the 96 young people aimed for in order to compare the self-reported SDQ data with results obtained from a community sample. Confidence intervals are reported for effect sizes to provide an indication as to the reliability of the results.

Table 28: Study 4 - Response rate

Source	**Number of families sent information pack**	**Total number of children aged 11-16 years**	**Number of questionnaires returned**	**Response rate**
Hospital clinic	**Count**	**Count**	**Count**	**%**
A	3	4	4	100
B	5	10	6	60
C	9	10	7	70
D	9	12	7	58.3
Sub-total	25	36	24	66.7
NACC	53	66	50	75.8
Total	79	102	74	72.5

11.2.2 Preliminary Work On The Data

The preliminary work carried out prior to analysing the data is described below. This includes transformation of variables, the comparison of NACC and clinic samples, and missing data analysis.

The transformation of variables

As for the survey of parents, before carrying out any analysis, the distribution of interval level data and ordinal variables with at least a five-point score sale were explored to see if they were normally distributed. Based on histograms, and by examining skew and kurtosis ratings (see Appendix 33), it was clear that 14 variables were not normally distributed. Log transformation improved the distribution of two variables: 'self-report SDQ conduct score' and 'adolescent PTI scores'. The remaining twelve variables not improved by the transformation were treated as ordinal level data during the analysis (see Appendix 34 for details).

Comparison of NACC and clinic samples

As for the parents' survey, in order to obtain a reasonably sized sample, it was necessary to combine the NACC and clinic samples. Before doing so, a series of tests were carried out to compare the two samples in relation to both data collected from the young people's questionnaires, and data from the parent's questionnaires used to describe young people's family background (see Appendix 35 for full results). Unfortunately, it was not possible to test for differences on 13 out of the 54 variables (3 from the children's survey, 10 from the parents' survey), because low expected cell counts prohibited the use of chi-square analysis.

Out of the remaining 20 variables drawn from the young people's survey, there was an association between whether young people were recruited through NACC or clinic samples and one variable: whether they belonged to any teams, clubs or other groups with an adult in charge during the previous 12 months (χ^2= 4.409, df=1, p=0.036). Seventy-eight per cent of young people recruited through NACC belonged to a team, club or group, compared to only 54.2% of those recruited through clinics.

Out of the remaining 21 variables drawn from the parents' survey, differences between NACC and clinic samples were found in relation to three variables: parents' age (t=-2.132, df=56.26,p=0.037, 95% confidence interval of the difference from –4.9460 to -0.1548), (40.15 years), whether the parent with IBD had another illness (χ^2=3.944,df=1, p=0.047), and the frequency with which the parent attended an outpatient clinic for IBD (χ^2=10.556,df=3, p=0.014). Further examination of the data revealed that young people from the NACC sample were likely to have an older parent (mean age 42.70 versus 40.23 years), less likely to have a parent with another long term illness (34.0% versus 58.3%), and the parent attended outpatient clinics less frequently than those recruited through clinics (8.3 % attending once a month or more, compared to 33.3% of those from NACC).

Given that there were significant differences on so few variables, and none of the main outcomes measures for young people, it was considered acceptable to combine the samples.

Missing data

There were missing data on a large number of variables, but as in the survey of parents, in most cases 5 per cent or less of the data were missing and therefore not of great concern. There were two variables in which more than 5 percent of the data were

missing: SDQ total difficulties score (8.11%; 6/74); and whether the child had a long term illness, health problem or disability (10.8%; 8/74). As in the survey of parents, pairwise deletion of cases was used to deal with missing data.

11.2.3 Characteristics Of Participants

Forty (54.1%) males and 34 (45.9%) females, aged between 11 and 16 years (mean age 13.36 years), took part in the survey. Most young people had two parents living at home (91.9%; 68/74), and it was usually the young person's mother (85.1%; 63/74), rather than father, who had IBD. In 13.7% (9/66) of cases the young person had a long-term illness, health problem or disability, which limited his/her daily activities. These included allergies, autistic spectrum disorder, asthma, attention deficit disorder, dyslexia, eczema, irritable bowel syndrome, learning difficulties, albinism and UC.

Overall the socio-demographic profile of families was highly similar to that reported in the parents' survey. Almost all the survey participants were drawn from families in which the parent with IBD was white (95.9%; 71/74). Respondents were largely drawn from households representing managerial and professional occupations (60.3%;44/73), and in the majority of cases (65.7%;48/73) parents had qualifications up to, or equivalent to, A level or vocational qualification level 3. Parents with IBD were often working (40.5% or 30/74 part-time, and 24.3% or 18/74 full-time). In families where there was another parent living in the house, this parent usually worked (83.8% or 57/68 full time, 8.1% or 6/68 part-time). The financial situation of families varied considerably, but most were 'doing alright' (28.4%; 21/74) or 'just about getting by' (29.7%; 22/74).

This sub-sample and the larger sample were also similar in terms of many aspects of the parent's health. The most common diagnosis was CD (56.8%), followed by UC (40.5%) (see Table 29).

Table 29: Study 4 - Parents' diagnosis

Diagnosis	Number of children (%)
Crohn's Disease (CD)	42 (56.8)
Ulcerative colitis (UC)	30 (40.5)
Crohn's colitis	1 (1.4)
Microscopic colitis	1 (1.4)

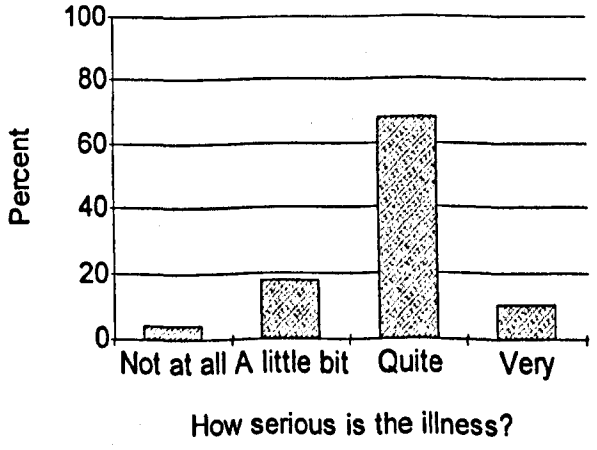
On the SIBDQ, scores ranged from 1.80 to 6.40, with a mean of 4.34 (SD= 1.23, 95% confidence interval from 4.04 to 4.64). During their life, 45.9% (32/72) had been through surgery for IBD. Most parents (94.6%;70/74) were prescribed regular medication for IBD,

including steroids (58.1%;43/74) and immunosuppressants (43.2%;32/74). Furthermore, levels of anxiety and depression, were similar to that reported previously, with 37.8% having anxiety and 14.9% depression, based on Snaith and Zigmond's criteria for mild to moderate cases.

However, there were some differences between this sub-sample, and the larger sample of parents. Parents of this sub-sample had symptoms of IBD for longer than in the larger parent survey (between 1.5 and 25 years, median 12 years). They had also experienced more medical interventions due to IBD. For example, a slightly larger proportion had stayed overnight in hospital for tests, treatment, or surgery due to IBD at some point in their life (81.08%; 60/74), and had a permanent ileostomy, ileoanal pouch or colostomy (10.8%;8/74). Within the past year, a larger proportion had stayed overnight in hospital (35.1%;26/74), been through surgery (17.6%;13/74), and were prescribed regular medication for IBD (94.6%;70/74) than in the whole sample. In addition, more parents in the sub-sample had another long term illness, health problem or disability, which limited their activities or the work they could do (41.9%;31/74).

When asked about their parent's health, most young people (68.1%; 49/72) felt their parent's illness was 'quite serious' (see Figure 7 for full range of responses). When asked how much they had talked to their Mum or Dad about their illness before they took part in the survey, the most common response (58.9%; 43/73) was that they had 'talked a little'. A further 28.8% (21/73) had 'talked a lot' and 12.3% (9/73) had 'never talked' to their parent about the illness.

Figure 7: Study 4 - Perception of the seriousness of the parent's illness



11.2.4 Survey Findings

Young people's social activity with peers

Young people had active social lives, with 79.8% saying they spent some or all of their spare time with friends. They were also very involved in organised activities with peers, with 70.3 % belonging to a team, club or group with an adult in charge during the past 12 months. The frequency with which they visited a friend's house was greater than the frequency with which they had friends visit their home (67.6% versus 59.5% said they did this all or some of the time (see Table 30 for further details).

The social activity scores, based on summing responses to the four items on social life, ranged from 0 to 10 (10 being the maximum level of social activity), with a median of 7.0.

Table 30: Study 4 - Level of 11- 16 year olds social activity with peers

1. How much time do you spend together with friends.....	**% (Count)** **N= 74**
All of your spare time	15 (20.3)
Some of your spare time	44 (59.5)
A little time	12 (16.2)
Not at all	3 (4.1)
2. How often do friends come to your house.....	
All or most of the time	5 (6.8)
Some of the time	39 (52.7)
A little of the time	26 (35.1)
Not at all	4 (5.4)
3. How often do you go to your friend's house.....	
All or most of the time	7 (9.5)
Some of the time	43 (58.1)
A little of the time	20 (27.0)
Not at all	4 (5.4)
4. Over the past 12 months have you belonged to any teams, clubs or other groups with an adult in charge?	
Yes	52 (70.3)
No	22 (29.7)

Table 31: Study 4 - Comparison of children's level of social activity with that reported in a British community sample.

	Study sample **11-15 year olds** **N= 64** **% (Count)**	**British community sample** **11-15 year olds** **N= 4326** **%**
1. How much time do you spend together with friends.....		
All of your spare time	20.3 (13)	23
Some of your spare time	60.9 (39)	65
A little time	14.1 (9)	11
Not at all	4.7 (3)	1
2. How often do friends come to your house.....		
All or most of the time	6.3 (4)	16
Some of the time	53.1 (34)	56
A little of the time	35.9 (23)	24
Not at all	4.7 (3)	4
3. How often do you go to your friend's house.....		
All or most of the time	9.4 (6)	16
Some of the time	60.9 (39)	60
A little of the time	25.0 (16)	21
Not at all	4.7 (3)	3
4. Over the past 12 months have you belonged to any teams, clubs or other groups with an adult in charge?		
Yes	73.4 (47)	73
No	26.6 (17)	27

Next young people's social activity was compared with that reported in a British community sample of 11-15 year olds (Meltzer *et al.*, 2000). Table 31 reveals that young people's involvement in organised social activities, such as belonging to teams, clubs or other groups, was the same as in the community sample. However, a larger proportion of the study sample than the community sample said that they spent just a little time or no time at all with friends (18.8 % versus 12 %), that friends came to their house just a little of the time or not at all (40.6% versus 28%) and that they went to their friend's house a little of the time or not at all (29.7% versus 24%). To determine whether these differences were statistically significant, the binomial test of proportions was applied. Results of the binomial test on amount of free time spent with friends and how frequently they went to their friend's house, were non-significant (p=.071 and p=.179 respectively). However, there was a statistically significant difference in relation to friends coming to their house (p=.017).

Relationships with parents

Overall respondents' relationships with parents were good, with 67.1% talking to their mothers about things that mattered to them at least once a week, and 43.3% reporting this level of communication with fathers. Furthermore, quarrelling was infrequent, with 62.2% reporting that they quarrelled with their mother less than once a week or hardly ever, and 73.1% reporting that they quarrelled with fathers less than once a week or hardly at all (see Table 32-33 for further details).

Table 32: Study 4 - Frequency of talking to parents about things that matter

	How often do you.....	
	talk to Mum about things that matter to you? Count (%)	**talk to Dad about things that matter to you? Count (%)**
Most days	25 (34.2)	12 (17.9)
More than once a week	24 (32.9)	17 (25.4)
Less than once a week	11 (15.1)	18 (26.9)
Hardly ever	13 (17.8)	20 (29.9)
Total	*73 (100)*	*67 (100)*

Table 33: Study 4 - Frequency of quarrelling with parents

	How often do you.....	
	quarrel with your Mum? Count (%)	**quarrel with your Dad? Count (%)**
Most days	8 (10.8)	4 (6.0)
More than once a week	20 (27.0)	14 (20.9)
Less than once a week	25 (33.8)	22 (32.8)
Hardly ever	21 (28.4)	27 (40.3)
Total	*74 (100)*	*67 (100)*

Chi-square was applied to the data to test whether there was an association between the sex of the parent with IBD and how often young people talked to, and quarrelled with, their mother and father. However, low expected cell counts prohibited the use of the test, even after collapsing response categories.

Responsibilities within the home

When asked about responsibilities within the home, most respondents reported spending 'under 1 hour' or '1-2 hours' a week on chores (74.3%) (see Table 34 for further details on time spent).

Table 34: Study 4 - Time spent in a week doing chores

Time spent per week	Count	(%)
None or almost none	6	(8.1)
Under 1 hour	23	(31.1)
1-2 hours	32	(43.2)
3-5 hours	13	(17.6)
6 hours or more	0	(0)
Total	74	(100)

The majority (62.2%; 46/74) felt that the amount they did to help around the house was the same as others their age. Just 27 per cent (20/74) felt they did more and 10.8% (8/74) felt they did less.

Chi-square was applied to the data to test whether there was an association between the aforementioned variables and whether the child lived in a single parent or two-parent household. Unfortunately, low expected cell counts prohibited the use of the test, even after collapsing response categories.

Responses to a checklist of household tasks indicated that young people were most likely to be involved in the everyday household tasks, including keeping their room tidy, helping to prepare meals, washing /drying dishes, and tidying the house. However, the frequency of involvement with these tasks was low, with a substantial proportion (between 35.1% and 59.5%) only doing these tasks 'sometimes' (see Table 35) .

Table 35: Study 4 - Involvement in tasks to help parent

Task	Response				
	Never did this	***Sometime did this***	***Often did this***	***Did this all the time***	**Total involved in task**
	Count (%)				
Kept my room tidy	6 (8.1)	26 (35.1)	25 (33.8)	17 (23.0)	68/74 (91.9)
Helped Mum/Dad prepare meal	9 (12.2)	37 (50.0)	19 (25.7)	9 (12.2)	65/74 (87.9)
Washed/dried dishes	10 (13.5)	31 (41.9)	20 (27.0)	13 (17.6)	64/74 (86.5
Made drinks/snacks for Mum/Dac	10 (13.7)	37 (50.7)	17 (23.3)	9 (12.3)	63/73 (86.3
Tidied the rest of the house	15 (20.3)	44 (59.5)	12 (16.2)	3 (4.1)	59/74 (79.8
Went shopping for food	35 (47.3)	26 (35.1)	12 (16.2)	1 (1.4)	39/74 (52.7)
Stayed at home to make sure Mum/Dad was okay	34 (48.6)	28 (40.0)	8 (11.4)	_	36/70 (51.4)
Cooked lunch or dinner for Members of my family	38 (52.1)	23 (31.5)	12 (16.4)	_	35/73 (47.9)
Looked after a brother/sister	36 (52.2)	26 (37.7)	6 (8.7)	1 (1.4)	33/69 (47.8)
Washed/ ironed clothes	39 (52.7)	24 (32.4)	8 (10.8)	3 (4.1)	35/74 (47.3)

In addition, although 51.4% of young people had stayed at home to make sure mum or dad was alright, this was a fairly rare occurrence, with most (40%) saying they only did this sometimes. Similarly, 47.3% of young people said they looked after a brother or sister, but most (37.7%) only did this sometimes.

When given the opportunity to list any other things they did to help, two young people described tasks directly related to the parent's condition, such as calling an ambulance, talking to doctors and helping the parent to have a drink. Three mentioned emotional support (talking to parents about their fears and calming a parent down).

The impact of parent's health on school attendance

Just 10.8% (8/74) of respondents reported missing any school days during the past year because their parent had been unwell. Out of those that had been absent, most (85.7%; 6/7) said they had missed just 1-2 days, with the remainder missing 2-5 days.

Young people's perceptions of their emotional and behavioural difficulties

Based on self-reported SDQ impact scores, 17.6% (13/74) of young people had emotional and behavioural difficulties that reached the clinical cut off for caseness (4.1% or 3/74 rated as a probable case, 13.5% or 10/74 a definite case). SDQ symptoms scores are presented in Table 36. Since not all scale scores were normally distributed, median rather than mean scores are reported.

Table 36: Study 4 - Self-report SDQ median score for 11-16 year olds

SDQ scale	Females n=34	Males n= 40	Combined N = 74
Total difficulties	12	10	11.0
Emotional	5	3	4.0
Conduct	2	2	2.0
Hyperactivity	4	3	4.0
Peer	2	2	2.0

There was no association between case ratings and the young person's sex. However, when SDQ symptom scores were examined, females scored significantly higher than males in relation to emotional symptoms (z=-2.309; p=.021).

Next the findings on caseness were compared with a British community sample of young people aged 5-15 years (Meltzer *et al.*, 2000) using the binomial test of proportion. Table 37 provides details on the proportion reaching cut offs for clinical case within the two samples. Although there was no significant difference between the samples when the

proportion with probable and definite ratings were compared (18.7% versus 13.1%, p=.119), significantly more of the 5-15 year olds in study sample were categorised as a definite case (16% compared to 6%, p=0.001).

Table 37: Study 4 - Comparison of self-report SDQ case level emotional and behavioural difficulties with normative British data

Case level (Impact score)	Study sample Age band 11-15 years N=64	Normative British data Age band 11-15 years N=4228
	% (Count)	
No case (0)	81.3 (52/64)	86.8
Probable (1)	3.1 (2/64)	7.3
Definite (2+)	15.6 (10/64)	5.8
Total cases	18.7 (12/64)	13.1

The intention was to use the one-sample t-test to compare SDQ mean symptom scores with normative data. However, it was only possible to apply the statistic to two scores (total difficulties and emotional symptoms) since the remaining scores were not normally distributed, even after transformation. Results indicated significant differences between the study and the normative sample in relation to both variables (total difficulties t=2.365, df=58, p=.021, 95% confidence interval of the difference from 0.2561 to 3.0761; emotional symptoms t=3.513, df=60, p=0.001, 95% confidence interval of the difference from 0.4955 to 1.8062). The mean scores indicate that the study sample had more total difficulties and emotional symptoms than the normative sample (see Table 38).

Table 38: Study 4 - Comparison of self-report SDQ symptom scores with normative British data

Scale	Study sample Age band 11-15 yrs N=64 Mean (standard deviation)		Normative British data Age band 11-15 yrs N=4228 Mean (standard deviation)	
Total difficulties	12.0	(5.4)	10.3	(5.2)
Emotional	4.0	(2.6)	2.8	(2.1)

Unfortunately, it is not possible to judge how the prevalence of self-reported case level emotional and behavioural difficulties compares with other studies of children who have a parent with a chronic illness. Few studies have gathered such data from children and, in the studies that do report on this matter, measures other than the SDQ have been used to assess children's psychological adjustment (see Table 39). In addition, the studies differ

from the thesis survey in the proportion of males and females within the sample, and the age range of the children.

Table 39: Study 4 - Comparison of self-reported case level emotional and behavioural difficulties with previous studies on parental illness

Author	Sample of children	Parent's characteristics	Measure	Proportion of cases
Steele *et al* (1997a)	N= 65 7-18 years 32 males 33 females	Fathers with hemophilia 50% HIV seropositive	R-CMAS CDI Definite cases reported	8% on RCMAS 19% on CDI
Grant & Compas (1995)	N=55 11-18 years 22 males 33 females	Cancer On average 2 months since diagnosis	YSRS (Anxious/depressed sub-scale)	18% girls 0% of boys
Thesis Study 4	N=74 11-16 years 40 male 34 female	IBD Symptoms for a median of 12.5 years	SDQ	14.1% probable 13.5% definite

CDI = Child Depression Inventory; R-CMAS = Revised Manifest Anxiety Scale; SDQ= Strengths and Difficulties Questionnaire; YSRS = Youth Self-Report Scale.

Young people's prosocial behaviour

Self-reported SDQ prosocial behaviour scores were not normally distributed, so median rather than mean scores on this scale are reported (See Table 40). There was no statistically significant sex difference on this scale ($z= -1.422$;$p=.155$), although there was a trend for females to score more highly than males

Table 40: Study 4 - Self-reported SDQ median prosocial behaviour scores

SDQ scale	Females n=34	Males n = 40	Combined N = 74
Prosocial	8	7	8.0

Unfortunately, because the data was not normally distributed, it was not possible to use an independent sample t-test test to investigate differences between the survey and community sample. However, the mean scores suggest that the survey sample does not differ substantially from the community sample (See Table 41).

Table 41: Study 4 - Comparison of self-report SDQ prosocial behaviour scores with normative British data

Scale	Study sample Age band 11-15 yrs N=64 Mean (standard deviation)	Normative British data Age band 11-15 yrs N=4228 Mean (standard deviation)
Prosocial	7.6 (1.8)	8.0 (1.7)

Young people's support needs

Young people were asked about their need for four types of support. The most prevalent was 'information and advice about Mum/Dad's health' (81.7%), followed by 'someone to talk to about how I feel about Mum/Dad's health' (50.7%), 'to meet other young people whose Mum or Dad is sometimes unwell' (34.3%) and 'someone to help family with things around the house' (31.0%). However, in many cases needs were met. When young people's *unmet* needs were examined, only 36.6 % had an unmet need for information and advice and 14.1% for someone to talk to. In addition, only a small proportion had an unmet need to meet other young people whose Mum or Dad is sometimes unwell (17.1%) or for someone to help the family with things around the house (19.7 %).

Table 42: Study 4 - Young people's views on their support needs

Type of support	Response		
	Support need Count (%)	Unmet support need Count (%)	Total Count
1. Information and advice about Mum/Dad's health.	58 (81.7)	26 (36.6)	71
2. Someone to help my family with things around the house like cleaning and cooking.	22 (31.0)	14 (19.7)	71
3. To meet other young people whose Mum or Dad is sometimes unwell	24 (34.3)	12 (17.1)	70
4. Someone to talk to about how I feel about Mum/ Dad's health	36 (50.7)	10 (14.1)	71

Chi-square analysis was used to investigate whether support needs differed according to the child's sex, the parent's sex, and the parent's diagnosis (UC or CD) (see Appendix 36 for results). No association was found between any of the support needs and the child's sex. It was not possible to investigate the influence of parent's sex due to low expected cell counts. An association was found between parent's diagnosis and whether respondents wanted to meet other young people whose Mum or Dad is sometimes unwell ($\chi^2 = 3.897$, df=1, p=.048). Young people who had a parent with CD were more likely than those who had a parent with UC to report this support need (43.6% versus 20.7% respectively).

11.3 Part Two: Parents' Views

In the survey of parents reported in Chapter 10, in addition to being asked about their own experiences and support needs, respondents were also asked about their perception of the psychological adjustment and prosocial behaviour of all children in the family between 4 and 16 years of age, using the SDQ. Preliminary work prior to analysing the data, and the background of the parents who took part in the survey, are as described in Chapter 10.

Questionnaires were completed for 214 children, with a mean age of 9.38 years (SD=3.61). One hundred and ten of the children were male and 103 females (data on sex was missing for one child). Results were as follows.

11.3.1 Parents' perceptions of children's emotional and behavioural difficulties

Based on impact scores, 30.7% of the sample were categorised as being at risk of case level difficulties (18.9 % rated as definite and 11.8% as probable cases). SDQ symptoms scores are reported in Table 43. Since not all the scale scores were normally distributed, median, rather than mean scores, are presented.

No association was found between case rating and child's sex or age band. However, when SDQ symptoms scores were examined, significant differences according to age band (4-10 years and 11-16 years) were found in relation to total difficulties (z=-3.320; *p*=.001), emotional symptoms (z=-2.699;*p*=.007), conduct problems (z=-3.235; *p*=.001), and hyperactivity (z=-3.345;*p*=.001). In all cases, 4-10 year olds scored higher than 11-16 year olds, indicating that they had significantly more problems in these areas (see Table 43).

Table 43: Study 4 - Parent- reported median SDQ symptom scores split by age band

SDQ scale	4-10 years n= 133	11-16 years n= 81	Combined N=214
Total difficulties	12	8	10.50
Emotional	3	2	3.0
Conduct	2	1	2.0
Hyperactivity	4.5	3	4.0
Peer	2	2	2.0

In addition, statistically significant sex differences were found in relation to hyperactivity (z=-2.160;*p*=.031). Males scored higher on hyperactivity (See Table 44).

Table 44: Study 4 - Parent reported median SDQ scores split by sex of child

SDQ scale	Females n=103	Males n=110
Total difficulties	10.0	11.0
Emotional	3.0	2.0
Conduct	2.0	2.0
Hyperactivity	3.0	4.0
Peer	2.0	2.0

When findings were compared with normative data from a large-scale national survey of British children aged 5-15 years (Meltzer *et al.*, 2000), a much higher proportion of parents in the study sample reported their child had probable or definite case level difficulties (31.8% compared to 16.6% in 5-15 year olds). The binomial test of proportion indicated that this difference was statistically significant (*p*=<.001).

Table 45: Study 3 - Comparison of parent-reported SDQ case level emotional and behavioural difficulties compared with British normative data

Case level (Based on impact score)	Study sample Age band 5-15 years N= 186 % (Count)	Normative British data Age band 5-15 years (N=10298) % (Count)
No case (0)	68.3 (127)	83.4
Probable (1)	12.4 (23)	7.8
Definite (2+)	19.4 (36)	8.8
Total caseness	*31.8%*	*16.6%*

The intention was to use the one-sample t-test to compare SDQ mean symptom scores with normative data. However, this was only possible for three symptom scores (total difficulties, emotional symptoms and hyperactivity) since the remaining scores were not normally distributed, even after transformation. On all three scores, there was a statistically significant difference between the study and community sample. Results were as follows: total difficulties score t=5.625, df =181, *p*=<0.001 (95% confidence interval of the difference from 1.784 to 3.712), emotional symptoms scores t=6.141, df=186, *p*=<.001 (95% confidence interval of the difference from 0.754 to 1.467), and hyperactivity scores t= 2.929, df=185, *p*=.004 (95% confidence interval of the difference from 0.195 to 0.999). Mean scores indicate that in all cases the study sample scored higher than the community sample (see Table 46).

Table 46: Study 3 - Comparison of parent-reported SDQ symptom scores with normative British data

Scale	Study sample Age band 5-15 yrs N=188 Mean (standard deviation)	Normative data Age band 5-15 yrs N=10298 Mean (standard deviation)
Total difficulties	11.2 (6.6)	8.4 (5.8)
Emotional	3.0 (2.5)	1.9 (2.0)
Hyperactivity	4.1 (2.8)	3.5 (2.6)

An attempt was made to compare the rates of parent-reported case level emotional and behavioural difficulties with those reported by researchers investigating other parental chronic illnesses (see Table 47 for details of other studies).

Table 47: Study 3 - Comparison of parent-reported case level emotional and behavioural difficulties with previous studies on parental illness

Author	Sample	Parent's characteristics	Method & source of data	Proportion of cases
Nelson & While (2002)	N=80 8-16 years 34 males 46 female	Cancer Within first year of diagnosis	R-CMAS - self-report Rutter A - ill parent Rutter B - teacher	36% probable to definite case on at least one measure
Brandt & Weinert (1998)	N= 174 7-17 years 96 males 78 females	MS	CBCL-well parent	26% probable to definite case
Steele *et al* (1997a)	N= 65 7-18 years 32 males 33 females	Hemophilia Fathers only 50% HIV seropositive	CBCL- both parents	11% definite case
Welch *et al* (1996)	N= 120 6-11 years	Cancer Time since diagnosis not stated	CBCL- ill parent	*Children (6-10 years)* 0% with ill father 9.5% boys with ill mother 20% girls with ill mother *Adolescents (11-18 years)* 0% of boys with ill father 4% of boys with ill mother 12.5% girls with ill mother 9% girls with ill father
Howes *et al* (1994)	N= 32 4-18 years 14 males 18 females	Mothers with cancer On average 32.8 months since diagnosis	CBCL- ill parent	9% probable to definite case
Thesis Study 3	N=214 4-16 years 110 males 103 females	IBD Symptoms for a median of 10 years	SDQ - ill parent	11.8% probable 18.9% definite

CBCL =Child Behaviour Checklist; R-CMAS = Revised Manifest Anxiety Scale; SDQ= Strengths and Difficulties Questionnaire .

Research has demonstrated that the parent-completed version of the SDQ is comparable with the Rutter Questionnaire and the Child Behaviour Checklist (Goodman and Scott, 1996; Goodman, 1997). When the survey findings were compared with those obtained in studies which have used similar questionnaires, the rate of parent-reported difficulties in children who have a parent with IBD was slightly lower than reported in Nelson and While's (2002) study of children whose parent has recently been diagnosed with cancer, slightly higher than in Brandt and Weinert's study of MS and Steele's (1997a) study of fathers with haemophilia, and much higher than reported in Howes *et al's* (1994) study of mothers who have been diagnosed with cancer for some time. However, given that the studies differed in the age range of children involved, the proportion of males and females, and whether results are based on the perception of the ill parent, the well parent, or both parents, it would be unwise to draw any firm conclusions as to how children who have a parent with IBD compare with children whose parent have other conditions.

11.3.2 Perceptions of children's prosocial behaviour

Parent-reported SDQ prosocial behaviour scores were not normally distributed, so median rather than mean scores are reported. No statistically significant difference was found between 4-10 year olds and 11-16 year olds on this scale ($z=-1.227$;$p=.220$), although there was a trend for 11-16 year olds to score higher (median score 9 and 8 respectively). However, statistically significant sex differences were found ($z=-2.362$;$p=.018$), with females scoring higher than males on prosocial behaviour (median scores 9 and 8 respectively).

Unfortunately, because the data were not normally distributed, it was not possible to use an independent sample t-test test to investigate differences between the survey and a British community sample (Meltzer *et al.*, 2000). However, the mean scores suggest that the survey sample does not differ substantially from the community sample (study sample mean 7.8, SD 2.0; community sample mean 8.6, SD 1.6).

CHAPTER 12

Understanding Psychological Distress

12.1 Introduction

The survey of parents and children found that a significant proportion of people were experiencing psychological distress, in the form of anxiety and depression for parents, and emotional and behavioural difficulties for children. However, it is important to bear in mind that not *all* respondents experienced such difficulties. What then distinguishes those who experience distress from those who do not? The purpose of this chapter is to identify such factors. Conceptual models of factors predicting psychological distress (see Chapter 9 for details), developed from the previous qualitative research and the general literature on parental illness, were tested using regression analyses.

The first half of the chapter deals with the conceptual model predicting parents' psychological distress. The second half reports on the model predicting children's emotional and behavioural difficulties.

12.2 Part One: Factors Influencing Parents' Psychological Distress

The conceptual model of factors influencing parents' psychological distress was tested twice; once in relation to anxiety and once in relation to depression. Before carrying out the analysis some preliminary work was undertaken, including the preparation of variables and the analysis of missing data. Details of this work are given below. This is followed by a description of how variables were selected for inclusion in the model, and the results of testing for main effects, moderation, and mediation. A summary of the findings is given at the end of the section.

12.2.1 Preliminary work on the data

Preparation of variables for inclusion in analysis

In order to test the conceptual model of parents' anxiety and depression, modifications had to be made to two variables: the measure of IBD-related health status (SIBDQ) and parenting difficulty (PTI).

Although the SIBDQ provides a reliable and valid measure of an individual's IBD related health status in the previous two weeks, three of the items included in the scale assess psychological distress (Items 5, 8, and 10 – see Appendix 9 for further details). Therefore, if any association was found between SIBDQ and HADS scores, it might simply reflect similarities between the scales. It was therefore decided that a reduced SIBDQ score should be computed, omitting responses to these three items. The new SIBDQ score ranged from 1.29 to 7, with a mean of 4.48 and a standard deviation of 1.27. It was normally distributed (skewness = -.265; kurtosis =-.500), with no outliers.

Second, in relation to PTI data, some parents had children in more than one age band and therefore completed multiple PTI scales. For these cases, a decision had to be made as to which scale score to enter into the analysis. Since each scale was comprised of a different type and number of items, scores across the three scales were not comparable. Therefore PTI scores were converted to standardised scores. Next the data were explored to determine whether there was any difference in parents' response to the scales. Since the Wilcoxon Signed Ranks test revealed no significant differences (z= -0.533 for comparison between infant and child scales, p=0.59; z=-1.157 for comparison between child and adolescent scale, p=0.247), the average of the standardised scores was used in the analysis. To improve the distribution of this variable, the log transformation was applied.

Missing data analysis

For this element of the analysis, when there were missing data casewise deletion of variables was used. This meant the same cases were used in each step of the regression analysis, making it possible to assess the impact of adding variables to the model. Unfortunately, this resulted in the loss of a substantial number of cases. For example, only 132 out of the original 178 parents who took part in the survey were included in the analysis of parental anxiety and 133 cases included in the analysis of parental depression. Given that the sample size is smaller than the 200 aimed for at the outset of the study, efforts were made to minimise the number of independent variables included in the

analysis, and confidence intervals are reported for regression coefficients to provide an estimate of the reliability of the results

12.2.2 Step one- Selection of variables for inclusion in the analysis

Out of the 30 independent variables initially available for inclusion in the regression analysis, a total of six were selected for the analysis of parents' anxiety and eight for the model of parents' depression (see Table 48). The process by which other variables were eliminated is described below.

Table 48: Independent variables included in the analysis of parents' psychological distress

Independent variables included in analysis of anxiety and depression
Socio-demographics
• Perception of financial situation
• Parent's current work situation
Health
• SIBDQ minus psychological symptoms
• Presence of illness/health problem/disability other than IBD
Difficulties with parenting
Family support
Additional independent variables included in analysis of depression
Socio-demographics
• Single parent/ living with partner
Health
• Prescribed regular medication in past year

Review of variables

First, an initial review of the variables available for inclusion in the analysis led to the exclusion of two variables: frequency of outpatient appointments over the past year and ethnic group. Frequency of outpatient appointments was excluded because meetings with clinic staff revealed that outpatient clinics were run in different ways across the four research sites: some asked patients to attend regular check ups, others monitored patient's progress via telephone, making an appointment to see a patient only when their condition deteriorated. Therefore the variable is not a good indicator of illness severity, which is the only reason for including it in the analysis. Ethnic group was excluded because the sample is predominantly Caucasian.

Analysis of relationship between dependent and independent variables

Having excluded these two variables, bivariate analysis of the remaining 28 independent variables was carried out (see Appendix 37). Only variables statistically significant at the .05 probability level, or higher, were selected for inclusion in the regression analysis.

In relation to anxiety, there were significant associations with, or differences according to, 12 independent variables. These were SIBDQ minus psychological distress (r= -.48; *p*= <.001), whether prescribed medication in the last year (r=.16; *p*=.037), presence of another long term illness (r=.26;*p*=<.001), general perception of health (r=.42;*p*=<.001), parent sex (r=-.15;*p*=.049), whether currently living with a partner (r=-.175,*p*=.020), financial situation (r=.28;*p*=<.001), log of average standardised PTI scores (r=.36,*p*=<.001), parent's highest qualification (r=.20, *p*=.008), family socio-economic classification (r=.15; *p*=.044), family support (r=-.20; *p*=.013), and the respondent's work situation (F=6.26, df=2, 173, *p*=.002).

In relation to depression, there were also significant associations with, or differences according to, 12 independent variables. These were SIBDQ scores minus psychological distress (r= -.72; *p*=<.001), whether had an overnight stay in hospital within the last year (r=.17, *p*=.021), frequency of hospitalisations (r=.15, *p*=.046), whether prescribed regular medication in the last year (r=.27; *p*=<.001), whether prescribed steroids in last year (r=.18, *p*=.017), having another long term illness (r=.34; *p*=<.001), general perception of health (r=.58; *p*=<.001), whether currently living with a partner (r=-.26; *p*=<.001), financial situation (r=.27; *p*=<.001), log of average standardised PTI scores (r=.60; *p*=<.001), family support (r=.20; *p*=<.001), the respondent's work situation (F=11.09, df=2, 175, *p*=<.001), and whether patients had CD or UC (t=2.125;df =167.8; *p*=.035; 95% confidence interval from .093 to 2.54).

Given the small sample size, and the possibility of multicollinearity within groups of health and socio-demographic variables, it was decided that some of the aforementioned significant independent variables should be excluded from the analysis. First, patient's diagnosis (CD or UC) was dropped from the analysis since, if this variable was used, respondents who had other IBD diagnosis would be excluded from the analysis. Furthermore, since perceived health status differs significantly according to diagnosis (see Chapter 10, section 10.4), including this variable in the regression equation is likely to introduce collinearity into the model.

Second, it was decided that variables with correlation coefficients less than r= .20 should be excluded. In the model of parental anxiety, this eliminated four variables: whether prescribed medication in the last year, parent sex, whether currently living with a partner, and family socio-economic classification. In the model of parental depression, this eliminated three variables: overnight stay in hospital within the last year, frequency of hospitalisations, and being prescribed steroids.

Analysis of relationship between independent variables

Next, in order to check for collinearity between the remaining independent variables, bivariate analysis was carried out (see Appendix 38 for full details of results). Based on these results, a further two variables were excluded – general perception of health and parent's highest qualification. General perception of health was excluded because it is highly correlated with SIBDQ minus psychological symptoms (r=-.66). Furthermore, whereas the SIBDQ is an established reliable and valid measure, general perception of health is not, and, given that this survey is concerned specifically with the effects of IBD related health problems on psychological distress, it is more appropriate to use the SIBDQ score.

Parents' highest qualification was dropped from the analysis of parents' anxiety because there is evidence of collinearity between this variable and financial situation (F=6.555, df=3, 171, *p*=<.001). Furthermore, the initial analysis of the relationship between independent variables and anxiety demonstrated that anxiety was more highly associated with financial situation than with the parent's qualifications.

12.2.3 Step two - Testing for main effects

Having decided which independent variables to include, in order to test for main effects, variables were entered into the regression analysis hierarchically. In order to control for socio-demographic and support with parenting, these variables were entered first, followed by illness variables, and the measure of parenting difficulty. Results for the analysis of predictors of anxiety and depression are described in turn below.

The model predicting parental anxiety

In the model predicting parental anxiety, 25 per cent of the variance in HADS anxiety scores was explained by the parent's financial situation, work situation, family support, SIBDQ minus psychological symptoms, and whether s/he had another illness. However, after controlling for other variables, only *SIBDQ minus psychological symptoms* had a significant effect on anxiety, with decreasing symptoms associated with decreasing anxiety. Adding parenting difficulty to the model did not add significantly to the variance explained (see Table 49 and 50, Model 2).

Table 49: Hierarchical multiple regression of HADS anxiety scores- Table of coefficients

Independent variable	B	SE B	Standardised Beta	Tolerance	VIF	Sig.	95% Confidence interval for B	
							Lower	Upper
Model 1								
Constant	13.770	2.303				<.001	9.212	18.328
Socio demographics								
Financial situation	0.640	0.338	0.159	0.840	1.190	.061	-0.030	1.309
Part-time work	-0.539	0.823	-0.061	0.680	1.471	.514	-2.168	1.090
Full-time work	-0.544	0.897	-0.056	0.690	1.450	.545	-2.319	1.230
Family support	-0.033	0.032	-0.080	0.943	1.060	.315	-0.097	0.031
Parent's health								
SIBDQ minus psych	-1.236	0.336	-0.338	0.710	1.408	<.001	-1.901	-0.572
Presence of another illness	0.957	0.816	0.100	0.820	1.220	.243	-0.657	2.572
Model 2								
Constant	-1.511	10.783				.889	-22.853	19.831
Socio demographics								
Financial situation	0.500	0.350	0.124	0.776	1.288	.157	-0.194	1.193
Part-time work	-.0449	0.822	-0.051	0.676	1.479	.585	-2.076	1.177
Full-time work	-.0382	0.900	-0.040	0.679	1.473	.672	-2.163	1.399
Family support	-0.030	0.032	-0.074	0.940	1.064	.355	-0.094	0.034
Parent's health								
SIBDQ minus psych	-1.048	0.359	-0.286	0.617	1.622	.004	-1.758	-0.338
Another illness	0.900	0.813	0.094	0.818	1.223	.270	-0.709	2.509
Parenting difficulty (ASPTI)	6.371	4.393	0.137	0.662	1.510	.149	-2.324	15.065

SIBDQ minus psych= SIBDQ minus psychological symptoms; ASPTI = Log of average standardised PTI score

Table 50: Hierarchical multiple regression analysis of HADS anxiety scores - Model summary

Independent variable	R	R square	R square change	F change	Df	Sig. of F change
Model 1	.50	.25	.25	7.110	6,125	<.001
Model 2	.52	.27	.01	2.103	1,124	.149

The model predicting parental depression

In total 64 per cent of the variance in parents' depression was explained by socio-demographic variables (financial situation, respondent's work situation, whether they are living with a partner), family support, health variables (SIBDQ minus psychological symptoms, the presence of another illness, health problem or disability, whether prescribed medication in the last year), and parenting difficulty (See Table 51 and 52, Model 2). However, after controlling for other variables, only *SIBDQ minus psychological symptoms* and *parenting difficulty* are significant predictors of depression. Examination of the standardised coefficients reveals that SIBDQ score has a greater influence on depression then parenting difficulty.

Table 51: Hierarchical multiple regression analysis of HADS depression scores- Table of coefficients

Independent variable	B	SE B	Standard Beta	Tolerance	VIF	Sig.	95% confidence interval	
							Lower	Upper
Model 1								
Constant	16.922	2.029				<.001	12.907	20.938
Socio demographics								
Financial situation	0.172	0.239	.045	0.853	1.172	.472	-0.301	0.645
Part-time work	-0.938	0.601	-.111	0.669	1.495	.121	-2.128	0.252
Full-time work	-0.851	0.650	-.092	0.678	1.475	.193	-2.139	0.436
If living with a partner	-1.536	1.018	-.093	0.881	1.135	.134	-3.551	0.478
Family support	-0.017	0.023	-.005	0.930	1.075	.940	-0.048	0.044
Parent's health								
SIBDQ minus psych	--2.183	0.247	-.623	0.681	1.468	<.001	-2.672	-1.695
Another illness	0.760	0.599	.083	0.800	1.250	.207	-0.425	1.945
Medication in year	1.084	0.837	.078	0.932	1.073	.198	-0.573	2.740
Model 2								
Constant	-14.772	7.552				.053	-29.722	0.177
Socio demographics								
Financial situation	-0.090	0.231	-.024	0.795	1.257	.699	-0.548	0.368
Part-time work	-0.769	0.564	-.091	0.666	1.502	.175	-1.885	0.347
Full-time work	-0.531	0.613	-.058	0.668	1.497	.388	-1.744	0.682
If living with a partner	-1.272	0.954	-.077	0.877	1.140	.185	-3.160	0.616
Family support	-0.002	0.022	.005	0.929	1.077	.933	-0.041	0.045
Parent's health								
SIBDQ minus psych	-1.787	0.248	-.510	0.589	1.699	<.001	-2.278	-1.295
Another illness	0.671	0.560	.073	0.799	1.252	.234	-0.439	1.780
Medication in the last year	1.194	0.783	.086	0.931	1.074	.130	-0.356	2.744
Parenting difficulty (ASPTI)	13.045	3.009	.290	0.662	1.511	<.001	7.089	19.001

SIBDQ minus psych= SIBDQ minus psychological symptoms; ASPTI = Log of average standardised PTI score

Table 52: Hierarchical multiple regression analysis of HADS depression scores - Model summary

Independent variable	R	R square	R square change	F change	Df	Sig. of F change
Model 1	.76	.58	.581	21.500	8,124	<.001
Model 2	.80	.64	.056	18.798	1,123	<.001

12.2.4 Step three - Testing for moderators

Next the data were tested for moderators. As described in Chapter 9, it was hypothesised that the age of youngest child moderated the impact of parental illness on parenting difficulty. Therefore, the interactions between age of youngest child and the three illness variables selected for inclusion in the analysis (SIBDQ minus psychological symptoms, being prescribed medication in the last year, and presence of another illness) were tested. None were significant (see Appendix 39 for results).

In addition, in the prediction of anxiety and depression, interactions between the following variables were hypothesised :

- Parent sex and parenting difficulty
- Family support and parenting difficulty

When these interactions were tested (see Appendix 39 for full results), the only statistically significant interaction was between family support and parenting difficulty in the prediction of depression (R square change =.028; F change = 6.228; df=1,135; *p*= .014). The regression equation for the relationship between family support and parenting difficulty as predictors of depression, including the interaction term, is as follows:

Depression = (-.630 x z family support score) + (2.418 x z log average standardised PTI score) + (-.772 fssxapti) + 6.379

The interaction term was added to the hierarchical regression (see Table 53). This resulted in an R square change of .015 (F change =5.221; df=1, 122; *p*=.024). The final model explained 65% of the variance in depression scores.

Table 53: Hierarchical regression analysis of HADS depression including interaction term - Table of coefficients

							95% confidence interval	
Independent variable	**B**	**SE B**	**Std Beta**	**Tolerance**	**VIF**	**Sig.**	**Lower**	**Upper**
Constant	-16.610	7.470				.028	-31.397	-1.823
Socio demographics								
Financial situation	-0.090	0.228	-.024	.795	1.257	.690	-0.541	0.360
Part-time work	-0.744	0.554	-.088	.665	1.503	.182	-1.841	0.353
Full-time work	-0.480	0.603	-.052	.667	1.499	.427	-1.673	0.713
If living with partner	-0.804	0.960	-.049	.838	1.194	.404	-2.704	1.096
Family support (FSS)	-0.021	0.024	-.054	.765	1.308	.380	-0.068	0.026
Parent's health								
SIBDQ minus psych	-1.727	0.245	-.493	.582	1.718	<.001	-2.213	-1.241
Another illness	0.649	0.551	.070	.798	1.253	.241	-0.442	1.740
Medication in year	1.505	0.782	.108	.903	1.108	.057	-0.043	3.053
Parenting difficulty (ASPTI)	13.648	2.970	.303	.657	1.523	<.001	7.768	19.528
FSS X ASPTI	-0.588	0.257	-.138	.781	1.281	.024	-1.097	-0.079

SIBDQ minus psych= SIBDQ minus psychological symptoms; ASPTI = Log of average standardised PTI score

After controlling for other variables, the significant predictors were *SIBDQ minus psychological symptoms score* (a measure of perceived-IBD-related health status), *average standardised PTI score*, and the *interaction between family support and average standardised PTI*. Standardised coefficients reveal that perceived IBD-related health status had the greatest influence on HADS depression scores, followed by the parenting difficulty, and finally the interaction term. Increases in parenting difficulty were associated with increases in depression, whereas increases in perceived IBD-related health status were associated with decreases in depression.

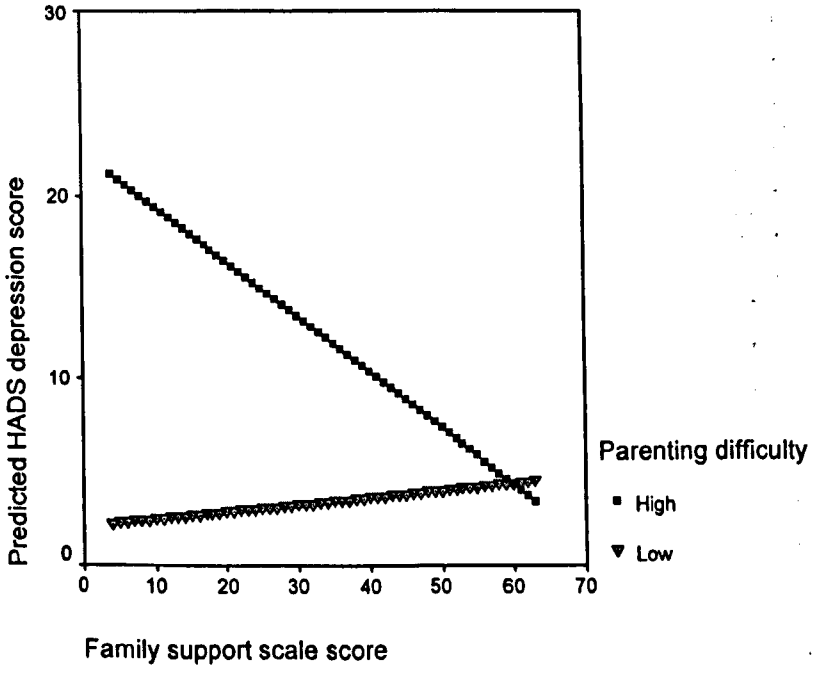
To interpret the interaction term, predicted scores were calculated for low and high levels of parenting difficulty and family support scores (see Table 54). Scores used to make predictions were taken from the range found within the study sample in order to avoid extrapolating beyond the survey data set.

Table 54: Depression scores predicted by interaction between family support and parenting difficulty

Independent variables	**Predicted HADS depression score**
Family support =4, log of average standardised PTI = 2.17	2.23
Family support =4, log of average standardised PTI = 2.59	21.19
Family support =63,log of average standardised PTI = 2.17	4.52
Family support = 63, log of average standardised PTI = 2.59	3.51

The results indicate that, when parenting difficulty is low, family support makes very little difference to parental depression. However, when parenting difficulty is high, support from others in bringing up their child/ren greatly reduces parental depression. Figure 8 illustrates this relationship.

Figure 8: The moderating influence of family support on the relationship between parenting difficulty and parental depression.



12.2.5 Step four - Testing for parenting difficulty as a mediator

Finally, the data were explored to test whether parenting difficulty played a mediating role in any relationship between severity of illness and anxiety or depression. In order to fulfil Baron and Kenny's (1986) criteria for mediation (see Chapter 9, section 9.10.3 for details), the previous regression analysis was used to test whether parental illness predicted depression/anxiety, and whether parenting difficulty predicted depression/anxiety after controlling for parental illness. In addition, it was necessary to carry out a further analysis to test whether parental illness was a significant predictor of parenting difficulty. Results are given below.

The model predicting parental anxiety

Perceived IBD-related health status (as assessed by SIBDQ minus psychological symptoms) was a significant predictor of parenting difficulty, even after controlling for socio-demographics and family support (see Table 55). However, as parenting difficulty was not a significant predictor of anxiety after controlling for illness variables (see Table 49, Model 2), there was no evidence to support the hypothesis that parenting difficulties mediate the relationship between health and anxiety.

Table 55: Testing whether parental illness variables predict parenting difficulty- Table of coefficients

Independent variable	B	SE B	Std beta	Tolerance	VIF	Sig.	95% Confidence interval	
							Upper	Lower
Model 1								
Constant	2.430	.057				<.001	2.317	2.542
Socio demographics								
Financial situation	.020	.007	.238	.853	1.172	.003	0.007	0.033
Part-time work	-.013	.017	-.069	.669	1.495	.442	-0.046	0.020
Full-time work	-.025	.018	-.120	.678	1.475	.179	-0.060	0.011
If living with a partner	-.020	.028	-.056	.881	1.135	.477	-0.076	0.036
Family support	-.000	.001	-.032	.930	1.075	.673	-0.002	0.001
Parent's health								
SIBDQ minus psych	-.030	.007	-.391	.681	1.468	<.001	-0.044	-0.017
Another illness	.007	.017	.034	.800	1.250	.682	-0.026	0.040
Medication in year	-.008	.023	-.027	.932	1.073	.718	-0.055	0.038

SIBDQ minus psych= SIBDQ minus psychological symptoms

Table 56: Testing whether parental illness predicts parenting difficulty - Model summary

Independent variable	R	R square	R square change	F change	Df	Sig. of F change
Model 1	.58	.34	.338	7.916	8,124	<.001

NB Scatterplot of standardised residuals for parenting difficulty model suggests the data is heteroscedastic.

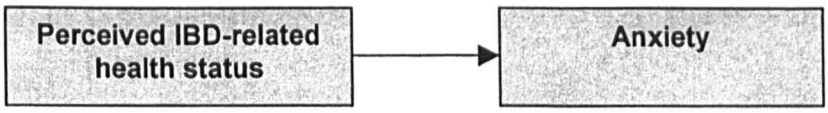
The model predicting parental depression

There was evidence that parenting difficulty was a partial mediator of the relationship between parental illness and depression. As already stated, the analysis of variables related to parental depression demonstrated that perceived IBD-related health status (SIBDQ minus psychological symptoms) was a significant predictor of depression, even after controlling for socio-demographics and family support (see Table 51, Model 1). Furthermore, perceived IBD-related health status was also a significant predictor of parenting difficulty (see Table 55-56). Finally, parenting difficulty remained a significant predictor of depression after controlling for perceived IBD-related health status (see Table 51, Model 2). However, given that the inclusion of parenting difficulty in the model did not result in the influence of SIBDQ minus psychological symptoms being eliminated, merely reduced (the slope coefficient falls from –2.183 to – 1.787), we must conclude parenting difficulty was only a partial mediator of the relationship between health and illness.

12.2.6 Summary of findings

In summary, only 25 per cent of the variance in HADS anxiety scores was explained by variables available from the survey. These were the parent's financial situation, work situation, family support, perceived IBD-related health status, and whether s/he had another illness. However, after controlling for other variables, only perceived IBD-related health status had a significant effect on anxiety, with decreasing symptoms associated with decreasing anxiety. There was no evidence to support the hypothesis that parenting difficulty mediates the relationship between parental illness and anxiety, nor to support the moderators included in the conceptual model. Figure 9 illustrates the results of the regression analysis.

Figure 9: Factors influencing parents' anxiety

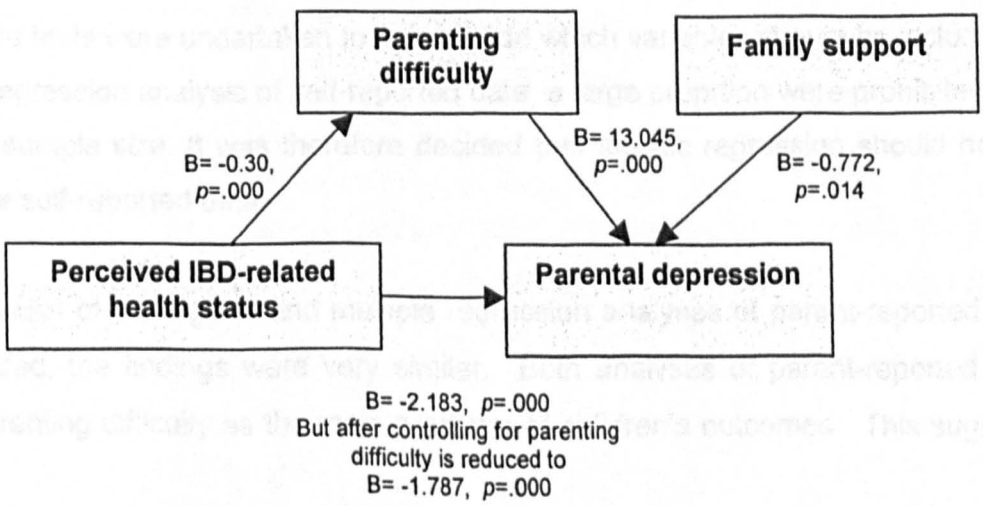


The regression analysis of factors predicting depression was much more successful, with the final model explaining 65% of the variance in HADS depression scores. This model included nine variables: socio-demographic variables (financial situation, parent's employment status, whether living with partner), family support, parent illness variables (SIBDQ minus psychological symptoms, whether the parent has another illness, health problem or disability, and whether prescribed medication in the last year), parenting difficulty, and the interaction between family support and parenting difficulty. However, after controlling for other variables, the significant predictors were perceived IBD-related health status, parenting difficulty, and the interaction between family support and parenting difficulty.

Perceived IBD-related health status had the greatest influence on HADS depression scores, followed by the parenting difficulty, and finally the interaction term. Increases in health status were associated with decreases in depression and increases in parenting difficulty associated with increases in depression. In relation to the interaction, when parenting difficulty was low, family support made very little difference to parental depression. However, when parenting difficulty was high, support from others in bringing up their child/ren greatly reduced parental depression.

In addition to this, there was evidence that parenting difficulty was a partial mediator of parental depression. Figure 10 illustrates the final model.

Figure 10: Factors influencing parents' depression



12.3. Part Two: Factors Influencing Children's Emotional And Behavioural Difficulties

When testing the conceptual model of factors influencing children's emotional and behavioural problems, both parent-reported and self-reported data were available for analysis. As discussed in Chapter 9, it is known that such scores are not highly correlated. The author of the SDQ (Goodman *et al.*, 2000; 1998) suggests that parent-reported data, aside from providing an insight into parent's perception of their child, is a good predictor of clinical status. In contrast to this, self-report data is best treated as providing an insight into young people's self-perception. Therefore, it was decided that the two sources of data should be analysed separately.

It is important to note that results of the two analyses are not directly comparable since they are based on different samples: the parent-reported data on a sample of children aged 4-16 years, self-reported data on a smaller sample of 11-16 year olds. Furthermore, the analysis of factors predicting self-reported SDQ symptom score included a number of additional independent variables taken from the survey of 11-16 year olds, not available for younger children.

Both the parent and self-reported SDQ provided two measures of children's emotional and behavioural difficulties - SDQ total difficulties scores and SDQ case ratings. An analysis based on total difficulties scores provides information on factors likely to increase emotional and behavioural symptoms, whereas an analysis based on caseness indicates factors that increase the likelihood of a child having difficulties severe enough to require intervention.

Initially the conceptual model was tested in relation to both outcome measures. However, when bivariate tests were undertaken to help decide which variables should be included in the logisitic regression analysis of self-reported data, a large proprtion were prohibited due to the small sample size. It was therefore decided that logistic regression should not be applied to the self-reported data.

When the results of the logistic and multiple regression analyses of parent-reported data were compared, the findings were very similar. Both analyses of parent-reported data identified parenting difficulty as the main predictor of children's outcomes. This suggests

that the multiple regression analysis is identifying predictors of clinically significant symptoms, and that it is unnecessary to report the results of both analyses. Given that the multiple regression analysis explained slightly more of the variance in the outcome measure than the logistic regression (R^2 = 33 per cent versus R^2_L =.26), and that it is generally advised that investigators base multi-variate analysis on scale scores rather than binary outcome measures (see Chapter 9, section 9.10.3 for further discussion), the regression analysis of SDQ total difficulties scores is reported.

The section opens with the multiple regression analysis of parent-reported data, before moving on to the analysis of self-reported data.

12.3.1 Model based on parent-reported SDQ total difficulties scores

Preliminary work on the data

As explained in Chapter 9, the first step in carrying out the regression analysis was to create a sub-sample of one child, selected at random, per family. There were 145 children in this sub-sample. It was anticipated that the sample size would be reduced further by casewise deletion of missing data during the analysis. Therefore care was taken to minimise the number of variables entered in to the analysis and to report confidence intervals for regression coefficients.

Most of the variables included in this analysis had already been explored for the descriptive analysis of the parent's data. However, the distribution of the parent-reported SDQ total scores was checked for this sub-sample. Results confirmed that these data were normally distributed and multiple regression could be applied. One new variable was created. For this analysis, parenting difficulty was represented by the parent's PTI score that matched the age range of the child being assessed. After exploring the data, the log transformation was applied to this variable to correct for it not being normally distributed.

Step one - Selection of variables

Out of the 31 independent variables initially available for inclusion in the analysis, a total of 10 were selected (see Table 57). The process by which others were eliminated is described below.

Table 57: Independent variables included in the regression analysis of parent-reported SDQ total difficulties scores

Child variables
• Child's age
• If child has an illness, health problem or disability
Socio-demographics
• Perception of financial situation
• If living with a partner
• Parent's current work situation
Parent's health
• SIBDQ minus psychological symptoms
• Presence of illness/health problem/disability other than IBD
Difficulties with parenting
Parent's psychological distress
• Anxiety
• Depression

First, associations between independent variables and SDQ total difficulties scores were examined. Full results of these tests are given in Appendix 40. Only variables statistically significant at the .05 probability level or higher were selected for inclusion in the regression analysis. In total 13 such variables were identified. These included health variables (SIBDQ scores minus psychological health, r= -.28; whether parent has another long term illness r=.28; parent's general perception of health, r=.23), parent's psychological distress (anxiety, r=.30; depression, r=.34), and socio-demographic variables (parent's age, r=-.28; financial situation, r=.27; whether parent is living with a partner, r-.18; respondent's work situation, F=3.301, df=2,118, *p*=.040; and partner's work situation, F=3.447, df=2,136, *p*=.035), log standardised PTI score (r=.41) and child variables (child's age, r=-.23; whether the child has an illness, disability or long term illness, r=.19).

Given the small sample size, and the possibility of collinearity between variables, it was decided that not all variables should be included in the model. First, parent's age was omitted because it was not expected to explain any of the variance in children's emotional and behavioural difficulties, except by confounding with child's age. Second, parent's general perception of health was omitted because, out of the health variables, it had the smallest effect size. It was also highly correlated with the SIBDQ score minus psychological symptoms (r=-.65) and whether the parent had another illness (r=.52). Finally, partner's work situation was dropped from the analysis since the work situation of the parent with IBD was included, and there was a significant association between the two variables (χ^2 =12.55, df=4, *p*=.014).

These decisions left 10 variables for inclusion in the analysis. One final check for collinearity between independent variables was carried out (see Appendix 41 for results), but no further variables were excluded from the regression analysis.

Step two - Testing for main effects

In order to test for main effects, the 10 independent variables were entered hierarchically, with child variables and socio-demographic variables entered first to control for their effect on other variables.

Together eight variables explain 33 per cent of the variance in parent-reported SDQ total difficulties scores (see Table 58 and 59, Model 2). These included child variables (whether the child has an illness, health problem or disability, and child's age), socio-demographic variables (financial situation, whether living with a partner, respondent's work situation), parent's illness (whether the parent has an illness, health problem or disability in addition to IBD, SIBDQ scores minus psychological distress) and parenting difficulty. However, after controlling for other variables, only three had a significant effect on outcomes for children - *the child's age, parenting difficulty, and whether the child has an illness, health problem or disability.* Increases in child age were associated with a reduction in parent-reported emotional and behavioural difficulties, whereas the child having an illness, health problem or disability, and increases in parenting difficulty, were associated with an increase in the child's difficulties. The standardised coefficients indicated that parenting difficulty and age of child had a similar level of effect on parent-reported symptom scores, and a greater influence than that exerted by whether the child has an illness, health problem or disability. However, in reporting these effects it is important to acknowledge that the final model was based on a sample of just 113 young people, and confidence intervals for the coefficients are large.

It is worth noting that parental anxiety and depression did not add significantly to the model (see Table 59, model 3). Tolerance and VIF statistics suggest that this may be partly due to multicollinearity between parental depression and other independent variables. The VIF statistic for depression is 3.43, a score which comes close to the cut-off of 4 often used to indicate that collinearity is a serious problem (Miles and Shevlin, 2001).

Table 58: Hierarchical multiple regression analysis for parent-reported SDQ total difficulties scores - Table of coefficients

Independent variable	B	SE B	Std Beta	Tolerance	VIF	Sig.	95% confidence interval	
							Lower	Upper
Model 1								
Constant	18.585	4.338				<.001	9.982	27.187
Child variables								
If child has an illness	4.333	2.008	.183	.969	1.032	.033	0.352	8.315
Child's age	-0.571	0.155	-.320	.930	1.076	<.001	-0.878	-0.265
Socio-demographics								
Financial situation	1.311	0.561	.213	.842	1.188	.021	0.199	2.423
If living with a partner	-1.806	2.090	-.076	.894	1.119	.390	-5.951	2.340
Dummy - part-time work	-1.652	1.328	-.126	.672	1.487	.216	-4.286	0.981
Dummy - full-time work	0.162	1.507	.011	.676	.1.479	.915	-2.827	3.151
Parent's health								
If parent has another illness	1.869	1.384	.132	.723	1.383	.180	-0.875	4.614
SIBDQ minus psych	-0.936	0.556	-.172	.665	1.504	.095	-2.037	0.166
Model 2								
Constant	-28.856	17.875				.110	-64.307	6.596
Child variables								
If child has an illness	3.919	1.954	.165	.963	1.038	.047	0.044	7.795
Child's age	-0.496	0.153	-.277	.899	1.112	.002	-0.798	-0.193
Socio-demographics								
Financial situation	0.948	0.560	.154	.794	1.259	.094	-0.164	2.059
If living with a partner	-1.004	2.049	-.042	.876	1.142	.625	-5.068	3.061
Dummy - part-time work	-1.137	1.302	-.087	.658	1.519	.385	-3.720	1.446
Dummy - full-time work	0.959	1.491	.065	.650	1.538	.522	-1.999	3.917
Parent's health								
If parent has another illness	2.145	1.347	.152	.719	1.391	.114	-0.526	4.816
SIBDQ minus psych	-0.318	0.585	-.059	.565	1.769	.588	-1.477	0.841
Log standardised PTI	19.052	6.977	.276	.641	1.559	.007	5.215	32.889

Continued...

Independent variable	B	SE B	Std Beta	Tolerance	VIF	Sig.	95% confidence interval	
							Lower	Upper
Model 3								
Constant	-29.356	18.798				.122	-66.647	7.936
Child variables								
If child has an illness	3.769	1.973	.159	.955	1.047	.059	-0.145	7.684
Child's age	-.502	0.154	-.281	.897	1.115	.001	-0.806	-0.197
Socio-demographics								
Financial situation	0.826	0.581	.134	.746	1.340	.158	-0.327	1.979
If living with a partner	-1.162	2.071	-.049	.867	1.153	.576	-5.270	2.947
Dummy- for part-time work	-1.019	1.318	-.078	.650	1.538	.441	-3.634	1.595
Dummy - for full-time work	1.041	1.504	.070	.647	1.546	.491	-1.943	4.024
Parent's health								
If parent has an illness	2.083	1.389	.148	.683	1.463	.137	-0.673	4.839
SIBDQ scores minus psych	-0.331	0.665	-.061	.442	2.260	.619	-1.650	0.987
Log standardised PTI score	19.170	7.886	.278	.508	1.969	.017	3.526	34.814
Parent's distress						.		
Parental anxiety	0.141	0.158	.097	.560	1.786	372	-0.172	0.454
Parental depression	-.079	0.235	-.050	.292	3.430	.739	-0.545	0.388

Table 59: Hierarchical multiple regression analysis of parent-reported SDQ total difficulties scores - Model summary

Independent variable	R	R square	R square change	F change	Df	Sig. of F change
Model 1	.53	.28	.277	4.986	8,104	<.001
Model 2	.57	.33	.049	7.457	1,103	.007
Model 3	.58	.33	.005	0.407	2,101	.667

Step three - Testing for moderators

The moderating influence of child's age on the relationship between parental illness (SIBDQ minus psychological symptoms and whether the parent has an illness other than IBD) and parenting difficulty was tested. No interaction effects were found.

The next step was to test whether family support moderated the influence that parent's depression, parent's anxiety, parenting difficulty and frequency of parental hospitalisation had on young people's emotional and behavioural difficulties, as hypothesised in the conceptual model. Again, results indicated no interaction effects (see Appendix 42).

Step four - Testing for mediation

Finally, the intention was to examine the data for evidence of mediators of the relationship between parental illness and children's emotional and behavioural difficulties. However, since parental illness had no effect on outcomes for children once socio-demographic circumstances and child variables were taken into account, it was unnecessary to do so.

12.3.2 Model based on self-reported SDQ total difficulties scores

Preliminary work on the data

The first step in carrying out the regression analysis on children's SDQ sores was to create a new sub-sample consisting of one child per family, selected at random. This resulted in a sample of 59 young people aged 11-16 years. Once again, the sample size achieved fell short of the 200 aimed for at the outset of the study. As in the previous regression analysis, care was taken to minimise the number of variables entered in to the analyses and confidence intervals are reported for regression coefficients.

The distribution of variables collected during the survey of young people has already been described in Chapter 11. However, this was based on the whole data set, so the distribution of variables had to be checked again for this sub-sample of one child per family (see Appendix 43 for skew and kurtosis ratings). As in the full data set, a number of variables were not normally distributed. Only one of these variables - the adolescent

PTI score, was improved by the log transformation. The remaining variables were treated as ordinal level data (see Appendix 44 for details).

Step one - Selecting variables for inclusion in the regression analysis

A total of 39 independent variables were initially available for inclusion in the analysis but only eight were significantly associated (p=.05 or higher) with self-reported SDQ total difficulties. These were: the frequency with which the child talked to their father about things that matter (r=.49), the frequency with which the child talked to their Mum about things that mattered (r=.35), log of adolescent PTI score (r=.33), parental depression (r=.32), whether the child had any illnesses, health problems or disabilities (r=.33), whether the child had missed school within the past year because the parent was unwell (r=.31), the frequency with which the child quarrelled with their Mum (r=-.28), and the extent to which the child had talked to their parent about IBD (r=-.27) (see Appendix 45 for results of all analyses undertaken).

Next, bivariate analysis of the aforementioned significant independent variables was undertaken to check whether there was evidence of collinearity (see Appendix 46 for full details of results). This indicated a significant association between parental depression and log of adolescent PTI score (r=0.73), and how frequently the child quarrelled with their mother (r=-.26). Adolescent PTI score was significantly associated with the frequency with which the child talked to their father (r=.33), and how frequently s/he quarrelled with their mother (r=-.34). Whether the child had an illness, health problem, or disability was significantly associated with frequency of talking to Dad (r=.30). The extent to which the child had talked to the parent about IBD was significantly associated with both how frequently the child talked to Mum (r=-.54) and Dad (r=-.38). Finally, the frequency with which the child talked to Mum was significantly associated with the frequency with which they talked to Dad (r=.53).

Given the size of the sample, no more than five variables could be entered into the analysis. First, it was decided that parental depression should be excluded since there was a highly significant association between it and parenting difficulties. Furthermore, the association between parenting difficulties and self-reported SDQ total difficulties was slightly stronger than between parental depression and self-reported total difficulties. Secondly, the frequency with which the child talked to their mother was excluded because it was significantly associated with the frequency with which the child spoke to the father and, out of the two variables, it had the weakest association with the dependent variable. Finally, it was decided that the extent to which the child had talked to the parent about IBD

should be excluded since, out of all the variables, it had the weakest association with the dependent variable. Table 60 lists the remaining five variables included in the analysis.

Table 60: Independent variables included in the regression analysis of self-reported SDQ total difficulties scores

Child variables
• If child has an illness, health problem or disability
Child's relationship with parents
• Frequency of talking to Dad
• Frequency of quarrelling with Mum
Whether child has missed school because of parent's illness
Difficulties with parenting

Two variables were ordinal (frequency of talking to Dad and frequency of quarrelling with Mum), and therefore required the creation of dummy variables in order to be entered in to the analysis. Given the small sample size, it was decided that this should be avoided and the variables were recoded in binary form (with 0 representing talking to Dad/quarrelling with Mum less than once a week, and 1 representing talking to Dad/quarrelling with Mum more than once a week). Bivariate analysis of the variables transformed to binary form confirmed that self-reported SDQ total difficulties scores differed significantly between the two groups (frequency of talking to dad t= -2.593, df=46, p=.013, 95% confidence interval of the difference -7.228 to –0.910; frequency of quarrelling with Mum t=2.694, df=52, p=.009, 95% confidence interval from 1.011 to 6.919).

Step two - Testing for main effects

The five selected variables were entered into the regression hierarchically. Parenting difficulties – the one significant variable hypothesised to influence children's adjustment, was entered last to test whether it had any influence after controlling for other variables. The analysis indicated that together three variables - whether the child has an illness, health problem or disability, the frequency with which s/he talks to their father about things that matter, and extent to which s/he quarrelled with their mother, explained 36 per cent of the variance in scores (see Table 61 and 62, model 2). However, only *the frequency of talking to their father* and the *frequency of arguing with their mother* were significant predictors after controlling for whether the child had an illness, health problem or disability.

Table 61: Hierarchical multiple regression analysis of self-reported SDQ total difficulties in 11-16 year olds - Table of coefficients

Independent variable	B	SE B	Standardised Beta	Tolerance	VIF	Sig.	95% confidence interval	
							Upper	Lower
Model 1								]
Constant	10.294	0.970				<.001	8.327	12.262
Whether child has an illness	4.206	2.990	.228	1.000	1.000	.168	-1.859	10.270
Model 2								
Constant	11.957	1.300				<.001	9.315	14.600
Whether child has an illness	1.559	2.666	0.085	0.893	1.120	.563	-3.860	6.977
Relationship with parents								
Talking to Dad	-5.547	1.638	-0.490	0.894	1.119	.002	-8.876	-2.219
Quarrelling with Mum	3.936	1.666	0.324	0.997	1.003	.024	0.552	7.321
Model 3								
Constant	11.946	1.319				<.001	9.263	14.629
Whether child has an illness	1.614	2.710	0.088	0.888	1.126	.556	-3.900	7.127
Relationship with parents								
Talking to Dad	-5.536	1.661	-0.489	0.893	1.120	.002	-8.915	-2.157
Quarrelling with Mum	3.761	1.799	0.309	0.879	1.138	.044	0.101	7.421
Missed school	1.061	3.752	0.042	0.875	1.143	.779	-6.573	8.695
Model 4								
Constant	9.022	5.805				.130	-2.803	20.847
Whether child has an illness	1.705	2.746	0.092	0.884	1.131	.539	-3.889	7.298
Relationship with parents								
Talking to Dad	-5.072	1.904	-0.448	0.695	1.439	.012	-8.951	-1.193
Quarrelling with Mum	3.376	1.996	0.277	0.752	1.329	.096	-0.628	7.380
Missed school	1.517	3.895	0.060	0.830	1.204	.700	-6.418	9.451
Log of adolescent PTI	0.863	1.668	0.088	0.684	1.462	.608	-2.534	4.260

Table 62: Hierarchical multiple regression analysis of self-rated emotional and behavioural difficulties - Model summary

Independent variable	R	R square	R square change	F change	Df	Sig. of F change
Model 1	.23	.05	.052	1.978	1,36	.168
Model 2	.60	.36	.313	8.363	1,34	.001
Model 3	.60	.37	.002	0.080	1,33	.779
Model 4	.61	.37	.005	0.268	1,32	.608

The regression coefficients indicated that when young people talked to their father about things that matter more than once a week, emotional and behavioural difficulties scores were reduced. When the young person argued with their mother more than once a week, emotional and behavioural difficulties were increased. Standardised coefficients confirm that the frequency of talking to their father had more influence on children's difficulties than the frequency of arguing with their mother. However, the confidence intervals for the regression coefficients were wide, indicating that estimates are not highly reliable, as might be expected with a small sample. The final model was based on a sample of just 38 young people.

Finally, it is worth noting that whether the child had missed school and parenting difficulty did not add to the variance explained by the model (see Table 61 and 62, Model 3 and 4).

Step three - Testing for moderators

The data were tested to see if family support moderated the influence of the following variables on self-reported SDQ scores:

- Adolescent PTI score
- Parental depression
- Parental anxiety
- Frequency of parental hospitalisation

No interaction effects were found (see Appendix 47).

In the original conceptual model, it was hypothesised that the child's social activity and perceptions of illness severity were affected by interaction between parental illness and child age. However, given that social activity and perception of illness were not significant predictors of young people's emotional and behavioural difficulties, there was little point in testing for these interactions.

Step four - Testing for mediation

Given that no health variables predict young people's self-reported emotional and behavioural difficulties, it was unnecessary to test whether parenting difficulty was a mediator, as proposed in the original model.

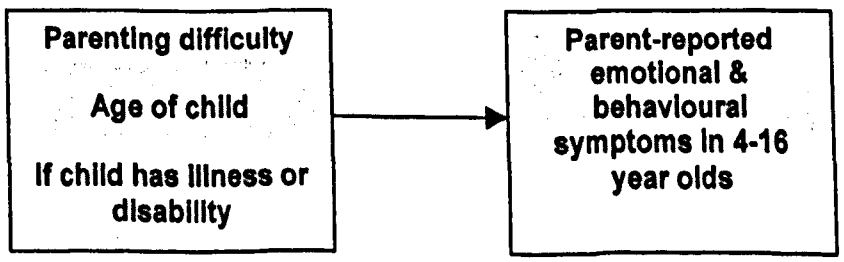
12.3.3 Summary of findings

When testing for predictors of children's emotional and behavioural difficulties care was taken to limit the independent variables entered into the regression equation to a number appropriate to the sample size. Nevertheless, the analyses were based on small data sets, particularly the analysis of self-reported emotional and behavioural difficulties, and findings should therefore be treated as exploratory, requiring confirmation by further research involving larger samples.

To summarise, 33 per cent of the variance in parent-reported SDQ total difficulties scores was explained by child variables (whether the child has an illness, health problem or disability, and child's age), socio-demographic variables (financial situation, whether living with a partner, respondent's work situation), the parent's illness (whether the parent has an illness, health problem or disability in addition to IBD, SIBDQ scores minus psychological distress) and parenting difficulty. However, after controlling for other variables, only three had a significant effect on parent-reported scores - the child's age, parenting difficulty, and whether the child has an illness, health problem or disability.

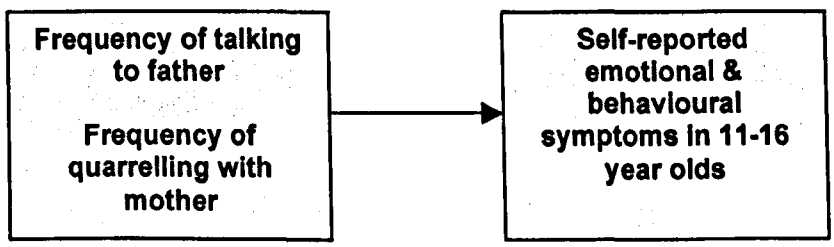
Increases in child age were associated with a reduction in parent-reported emotional and behavioural difficulties, whereas the child having an illness, health problem or disability, and increases in parenting difficulty, were associated with an increase in parent-reported difficulties. Parenting difficulty and age of child had the greatest, and similar level, of effect on parent-reported symptom scores. Figure 11 illustrates the results of the regression analysis.

Figure 11: Predictors of parent-reported SDQ total difficulties scores



When the model was tested on self-reported SDQ symptom scores, 36.5 per cent of the variance in scores was explained by whether the child has an illness, health problem or disability, the frequency with which the young person talked to their father about things that matter, and the frequency with which the young person quarrelled with their mother. However, after controlling for other variables, the frequency of talking to their father, and the frequency of arguing with their mother, were the significant predictors (see Figure 12 for summary).

Figure 12: Predictors of self-reported SDQ total difficulties scores



As the frequency with which young people talked to their father about things that matter increased, self-reported SDQ total difficulties scores were reduced. As the frequency with which a young person argued with their mother increased, self-reported SDQ total difficulties scores increased. Out of the two variables, frequency of talking to their father had more influence on children's difficulties.

Part V

Discussion

CHAPTER 13

Discussion

13.1 Introduction

The four studies carried out as part of this thesis provide a great deal of data on the experiences and support needs of parents with IBD. The purpose of this chapter is to reflect on the research as a whole, so that conclusions can be drawn about the support that should be provided to parents with IBD and their children.

The chapter begins by providing a brief overview of the strengths of the research, including its contribution to knowledge. In order to put the findings into context, this is followed by reflections on the research design and methods. Next, a summary of the findings is provided, including a discussion of the extent to which the findings fit with, and add to, the literature available at the point at which this thesis was completed. Recommendations are then made as to how parents who have IBD, and their children, might best be supported. This is followed by an acknowledgement of how the researcher's outlook on the investigation has changed during the course of the work. Finally, conclusions are drawn about the impact of IBD on parents and their children, and the support that should be provided.

13.2 An Overview Of The Strengths of The Research

This thesis represents the only investigation to date into the support needs of parents with IBD and their children. As such, it contributes both to the growing body of literature on parental illness, and to our understanding of how IBD affects the everyday lives of people with the condition. However, perhaps more importantly from the perspective of patients and practitioners, the findings from this research are highly relevant to clinical practice. Whereas most research on parental illness has simply described the experiences of parents and their children, by investigating support needs, the findings from this thesis offer clear guidance on how services to patients with IBD and their families might be improved.

Aside from contributing to knowledge, the other major strength of this thesis is the extent to which it has been welcomed by parents with IBD. At the outset of the work, it was unclear how receptive people with IBD would be to the research. Would a study focussing on their role as parents be considered worthwhile? It soon became apparent that parents with IBD were supportive of the research. During recruitment for Study 1, many welcomed the opportunity to take part in the research, commenting that they had never previously been asked how they were coping in relation to their role as parent. When Study 1 and 2 were completed, the findings were presented at a series of NACC meetings, which were well attended by parents with the condition. Following these presentations, I was contacted by a number of parents who wanted to thank me for carrying out the research, and to let me know how accurately the findings described their own experiences.

During phase two of the work, parents continued to respond positively to the research. In the screening questionnaire used to identify potential survey participants, respondents were given space in which to make additional comments. Twenty-seven parents chose to express their support for their research. Some wrote simply to thank me for undertaking the research, or to stress their willingness to participate in the study. For example:

> *I was so pleased to receive this as this disease has affected our lives so much. Just returned from another hospital admission. Thank you for your work.*

And

> *I am willing to help in anyway I can. Crohn's is very hard to understand and accept – you have good days and bad days and I am more than happy to answer any questions with the hope that it can help others.*

Many seemed particularly pleased that the research focussed on family life, believing that this was an aspect of IBD that was not receiving sufficient attention:

> *Thank you for showing an interest in the effect that this disease has on all members of the family. This side of things never gets much attention paid to it by consultants and other medical personnel, it seems to me.*

And

We have never taken part in any surveys before but when we saw the reason for this one, we were very interested as my UC has turned mine and my family's life upside down. My wife is currently undergoing treatment for cancer and so far her cancer has not affected our family as much as my UC!

Some clearly took part because they felt there was a need for greater support from service providers:

I think this research is long overdue. I've never had any help/services, and just getting xxxxxx (Child's name) *to school by 8.55 am everyday is a HUGE STRUGGLE. I wish you luck in your work.*

Given parents support for the research, it is hoped that practitioners will give some consideration to how they might go about implementing the recommendations that emerge from it.

13.3 Reflections On The Research Design And Methods

In this research, a mixed method approach, involving two qualitative and two quantitative studies, was used to investigate the experiences and support needs of parents with IBD and their children. There were a number of advantages to the overall research design. Study 1 – a qualitative study with parents with IBD, represented the first investigation into the impact of IBD on patients in their parenting role and on their children. By beginning with qualitative research, it was possible to gain an insight into the topic, something that was important since there was no previous research.

Nine months after data were collected from parents, the qualitative research with children (Study 2), was carried out. This allowed for an iterative process, in which the data from the research with parents provided ideas about issues to pursue during interviews with children. Also, carrying out the research in this order gave parents an opportunity to meet with the researcher, and develop an understanding of the purpose of the research, before being asked to give consent to their child taking part. It was hoped that this would alleviate any concerns parents had about the research, thereby encouraging them to allow their child to take part.

The findings from the qualitative phase were then used to design the quantitative phase of the research, a postal survey of parents with IBD, and another of their children aged 11-16

years. Through these surveys it was possible to establish the prevalence of the experiences and needs reported in the qualitative research, and test out hypotheses about factors that influenced the main outcome measures. This information was crucial to developing recommendations for service providers about the 'scale' of the difficulties experienced by parents with IBD and their children, and how they might best be supported. This investigation adds to previous research on the impact of chronic illness and disability on parents, in which the majority of researchers have collected qualitative data. In particular, whereas previous research with parents has suggested parents may be distressed by their experiences, none have attempted to assess the severity and prevalence of such difficulties to establish if this is an area where parents need support.

Nevertheless, there was one disadvantage to employing mixed methods, namely that it was difficult to integrate the findings from the four studies. As each study employed different methods, and was based on a different sample, when there were inconsistencies between study findings it was hard to be certain why this has occurred.

Finally, in relation to the overall research design, it should be acknowledged that, due to resource limitations, it was not possible to investigate in depth the experiences of the one remaining member of the immediate family – the parent without IBD. Data collected from parents with IBD during the course of this thesis suggests that this parent may have support needs in their own right. In some cases parents with IBD said that their spouse/partner had difficulty coming to terms with them having the condition, and might benefit from advice and information, or someone to talk about the situation. To fully understand whether the parent without IBD needs support, and what form it should take, requires further research in which data are gathered directly from this group of parents.

Below the strengths and limitations of each of the four studies undertaken during the course of the research are discussed in further depth.

13.3.1 Study 1

A major strength of Study 1 was that, by adopting a qualitative approach, parents were given an opportunity to provide an account of their experiences and support needs without researchers presupposing what these might be. However, as discussed in Chapter 6, it was a small-scale study, and the majority of participants had family members living close by who were able to offer them practical support with parenting. 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.

In Study 1, the intention was to collect data via 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 provide an insight into the difficulties some parents experience in their daily lives. In order to ensure parents who could not attend a focus group were not excluded, they were offered an individual interview. 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 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. In Study 1, this was overcome by asking parents to draw up a time line charting the effects IBD had on them as parents and on their children, and giving them different colour pens with which to note positive and negative experiences. In this way, they were actively encouraged to report positive experiences. The time line approach provided useful information on how parents' experiences change as the child develops. However, it also meant that retrospective data was collected, which is subject to recall error.

13.3.2 Study 2

As noted in Chapter 8, the qualitative research with children was very useful in giving younger children a voice, something that has been lacking in research on parental chronic illness. However, the data are limited in a number of ways. First, the data represent what participants *chose* to talk about; it may be that there are experiences related to having a parent with IBD too personal to be disclosed to a researcher. Second, the study was based on just 23 young people, drawn from 15 families, most of whom had a mother, rather than a father with IBD. Third, the youngest participant was six years of age so the research omits the experience of pre-school children, the age groups some parents said

they had most difficulty managing since they required so much care and attention. Fourth, the data includes retrospective data, which is subject to recall error.

Turning next to the methods employed, participants had a choice of taking part in an individual interview or a group interview with siblings. Although being flexible about how children took part helped ensure that more families participated than might otherwise have done, it should be acknowledged that there were disadvantages to group interviews. In group situations the children became very excited, competed with each other to complete drawings, and shouted out their response to the questions asked. The focus for the researcher was very much on ensuring that everyone got a chance to speak, and it was not possible to get individual's views on all issues covered in the topic guide.

In terms of techniques used to elicit data from children during interviews, eleven out of the 21 participants, who were aged eleven years or younger, took up the suggestion of using the visual aids provided during the course of the interview. This proved to be very helpful for a number of reasons. For younger children, it added to the fun of taking part, with children enjoying selecting coloured pens, paper, and stickers to work with. Initially, many of the participants seemed nervous about the interview. Drawing made the situation less formal and the child could talk without having to make direct eye contact with the researcher. It also gave the child greater control over the pace of the interview – the researcher could not move on to the next topic until the child had completed their drawing about the topic under discussion. It was explained to participants that their drawings would be used to illustrate the final report about the project written for young people, with at least one drawing selected from each person. This pleased both participants and their parent (see Appendix 48 for report written for 6-10 year olds, and Appendix 49 for report written for 11-20 year olds).

Although the visual aids were helpful, they increased the time it took to complete an interview. Unfortunately, parents of younger children tended to assume their children would not have much to say. They were also apprehensive about someone talking about their health with their children at great length. Therefore the time allocated to the interview was often limited, arranged to take place after school and before the children had their evening meal. This may have meant that children did not have opportunities to say everything they wanted to.

13.3.3 Study 3

As discussed previously, the main strength of the survey of parents with IBD is that it provides an indication of the extent to which the experiences reported in the qualitative research are prevalent in the wider population. For practitioners one of the most valuable aspects to the surveys is that they provide the first research evidence on parents' priorities for support. Although there were initially some difficulties in recruiting the sample size aimed for at the outset of the study, 178 parents took part in the research, a number that is more than sufficient for the descriptive analysis of the main outcome measure – HADS data on anxiety and depression. Given that substantial proportions of parents reported psychological distress, another important element of the survey is the identification of factors that increase the likelihood of anxiety and depression. This provides guidance on which groups of people are most likely to need psychosocial support and the form it should take.

Nevertheless, there are limitations to the conclusions that can be drawn from the survey. First, while the survey provides evidence on aspects of parents' lives that are going well, and areas where they are having difficulty, for the most part it is not possible to say whether these experiences differ from that of the general population since a control group was not included in the study. The availability of normative HADS data did mean that it was possible to compare levels of psychological distress in parents with IBD, and their children, with community samples. However, care must be taken not to attribute differences between community and survey samples to IBD per se. Instead, it may be due to any number of differences between families in which a parent has IBD and those of the general population. The regression analysis of factors predicting parents' anxiety and depression, and children's emotional and behavioural difficulties, was an attempt to understand the underlying causes of such difficulties. However, since the study was cross-sectional in design, significant results only indicate associations between variables. It is not possible to determine the direction of the relationship between variables, or whether the two variables are only associated because of their relationship to a third variable.

Moving on to consider the survey participants, first, the parents' survey was based on a convenience sample, and it is likely that respondents are drawn from families in which there are concerns about the impact of IBD on family life. Second, the majority of respondents were recruited through NACC, rather than hospital clinics as originally intended. While these two groups did not differ on many of the variables measured in the

survey, the NACC sample did have more support needs and it is therefore possible that it is not representative of the views of the general population of parents with IBD. Thirdly, despite efforts to recruit fathers into the parents' survey, 80 per cent of respondents were mothers. To compensate for this imbalance, sex differences in experiences and support needs were tested.

In terms of research methods, overall the parents' questionnaire seems to have been acceptable to parents, with 92.7% returning it complete. However, at the end of the questionnaire parents were given space to comment on the survey, and a number of issues were raised. First, an important point raised by a substantial number of parents is that IBD is a fluctuating condition, with an individual's disease activity and feelings of well-being varying over time. As the questionnaire asked about experiences within a particular time frame, responses may not be wholly representative of an individual's experiences. This was clearly a source of frustration to some participants. Seven parents said they had completed the parent's questionnaire as directed, despite responses not fully representing their experiences. For example:

> *My illness only affects me badly from time to time. My answers here are based within the time scale asked but I have not had a serious relapse in this time and so do not reflect my family's needs during times of real difficulty.*

Two parents said they had completed the whole, or a section of the questionnaire, as if they were having a flare up. For example:

> *A bit difficult filling it in because at the beginning of last year I had a severe bout of colitis when I was off work for a year and needed quite a few stays in hospital. So at that time I needed a lot of help, but it now is a lot better. In the section 'help needed by you' I answered as if I was in relapse.*

Parents also commented on how the survey did not pick up on the extent to which individual's lives were governed by IBD. For example:

> *I notice in reading the answers I have given, that it could appear as if my Crohn's disease does not interfere drastically with my life. This couldn't be further from the truth. Sadly I have just rearranged my entire life to revolve around my IBD.*

Finally, as explained in Chapter 9, the content of the survey was limited by data being collected via a postal questionnaire. This meant that some of the issues raised by the qualitative research could not be explored in depth in the survey. For example, restriction to family social life was not assessed as a separate variable, although it is encompassed within parenting difficulty, with the Parenting Task Index including a number of items on social activities.

13.3.4 Study 4

Many of the previous comments regarding the strengths and limitations of Study 3 also apply to Study 4. The research is useful in providing an estimate of the prevalence of young people's experiences and support needs, and factors that increase the likelihood of psychological distress. However, it is limited in not including a control group, being cross-sectional in design, and being based on a convenience sample, with the majority of respondents recruited through NACC, and most having a mother, rather than a father, with IBD.

Other limitations specific to the survey of young people include the fact that the researcher was reliant on the parents passing the survey questionnaire on to their child. Although the response rate was good (72.5%), it is possible that parents acted as gatekeepers, giving the questionnaire to some young people and not to others. Second, the sample size for the young people's survey was small (N=74), and fell short of the 96 young people aimed for at the outset of the study for the purposes of the descriptive elements of the analysis. Furthermore, it was necessary to select a random sample of young people for the regression analysis of self-reported emotional and behavioural difficulties, and this, combined with the effects of missing data, resulted in the final model being based on just 38 cases. As a consequence, confidence intervals for regression coefficients were wide, suggesting that estimates of effect sizes are not highly reliable and require confirmation by further research. Finally, it is worth bearing in mind that the survey only reports on the experiences of 11-16 year olds. The results of the qualitative research, and the survey of parents, suggest that younger children may well experience greater difficulties and have more need for support.

13.4 Summary Of The Findings

To recap, at the outset of the research the objectives were:

- To determine the impact of IBD (both positive and negative) on:
  parents in their parenting role;
  the adjustment of their children
- To identify factors which moderate and mediate this impact
- To gather parents and children's views on the support that would be helpful to families.

Below the findings on parents with IBD and their children are summarised in relation to these research objectives. This summary provides an overall picture of the results from all four studies, and uncovers areas of agreement and disagreement between studies. In addition, the extent to which the findings fit with, and add to, the literature available at the point at which this thesis was completed, is discussed. Findings on parents are reported first, followed by the findings on children.

13.4.1 Findings on parents

The impact of IBD on parents

Both the qualitative and quantitative research found that parents varied considerably in the extent to which they experienced difficulties with parenting. When they did have difficulties, the survey indicated they were most often in relation to household chores (between 46.7 and 50.4% had moderate to severe difficulty depending on the age range of their child), providing for financial needs (between 38.3 and 47.9% had moderate to severe difficulty), and social activities (between 16.7 and 48.9% had moderate to severe difficulty). Importantly, from the perspective of the child, in the survey it was rare for parents to report having difficulty with being physically affectionate, or talking and listening to their child.

The qualitative research shed some light on why parents had difficulties with parenting tasks. As might be expected, and in line with previous research with parents with other conditions (Smith and Soliday, 2001; Barlow *et al.*, 1999; Rehm and Catanzaro,1998; Wates, 1997; Association of Disabled Parents in Norfolk, 1996; Grimshaw, 1992; Geirdal, 1989) symptoms, including pain, fatigue, and nausea, made it difficult to carry out household chores, and limited social activities. The research also highlighted an issue

that may be unique to IBD and other gastrointestinal conditions; even when parents were relatively well, fear of incontinence and 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 due to lack of toilet facilities.

The qualitative research did not shed any light on the impact of IBD on parents' ability to provide for their children financially; this was not an issue addressed by the interview/focus group topic guide, or raised by participants. However, at the end of the parents' questionnaire eleven respondents choose to comment on financial difficulties, explaining that symptoms of IBD can reduce finances within the family, both by impacting on the earning potential of the ill parent, and that of their partner, who sometimes had to take on extra responsibilities within the home, so reducing their availability for employment.

When asked who had been helpful to them in bringing up their child, the survey found that family and friends were the most common sources of support to parents. Parents were most likely to perceive their immediate family as helpful sources of support, with the partner/spouse most frequently named as 'very' or 'extremely helpful' (66.1 %), followed by the respondent's parents (40.0%), the respondent's friends (24.0%), spouse or partner's parents (20.0%) and children (20.1%). Replicating findings in previous studies of parents with an illness/disability (Wates, 1997; Allaire, 1988), in the qualitative research parents explained that they preferred to turn to partner/spouse and close family for help, rather than friends and neighbours, fearing that this would be too much to burden them with.

In relation to statutory services, parents were most likely to consider hospital-based health professionals as helpful sources of support. However, only 17.6% rated them as 'very' or 'extremely helpful'. Such findings are in keeping with the qualitative research, in which parents said that support from members of the gastroenterology team in relation to their parenting role was provided on an ad hoc basis, depending on individual personalities and interests. Similar to parents with other illnesses/disabilities (Thomas, 1999; Association of Disabled Parents in Norfolk, 1996), participants had particular concerns about the support from generic health care staff since many of these staff had very little knowledge about their condition. It was notable that social services received very low ratings on helpfulness (only 1.8 % considered them to have been very or extremely helpful). This can be explained, at least in part, by the fact that the survey revealed that many parents

were not in contact with social services. However, it is also worth noting that in Study 1 the few parents who had sought help from social services were refused assistance.
The qualitative research suggested difficulties with parenting could lead to distress, particularly when the parent was a mother, and support from others was limited. When the extent to which parents were distressed was investigated through the survey, results indicated that a substantial proportion of parents were experiencing emotional difficulties severe enough to warrant intervention. Using criteria that identify clinically significant levels of anxiety and depression on the HADS (Crawford, 2001), 37.5% of parents were at risk of case level anxiety and 16.3% of case level depression. Care must be taken with these findings since they are based on a screening instrument and scores above clinical cut offs are only intended to indicate to clinicians that a patient *may* have a disorder (Clark and Harrington, 1999). As a result, the HADS, like any screening instrument, tends to overestimate the proportion that has difficulties severe enough for them to be considered a psychiatric case. Nevertheless, it is worth noting that, for both males and females, the prevalence of anxiety was substantively and statistically higher than reported in a recent UK community sample (Crawford, 2001). In addition, the rate of depression amongst females was also substantially and significantly higher than in the community sample.

A preliminary comparison of the prevalence of anxiety and depression with that reported in studies of IBD patients attending outpatient clinics (Guthrie *et al.*, 2002; Nordin *et al.*, 2002; Simren *et al.*, 2002; Porcelli *et al.*, 1994; Andrews *et al.*, 1987) suggests rates in the survey sample are greater. Further research involving a case-matched control group is needed to establish with greater certainty whether parents with IBD are more distressed than people without the condition and people with IBD who do not have parenting responsibilities.

Factors that influence parents' psychological distress

Given that anxiety and depression were so prevalent in the survey sample, regression analysis was used to test a conceptual model of factors that influence the level of distress experienced (see Chapter 9 for details of model). This revealed that 65% of the variance in HADS depression scores could be explained by variables available from the survey. After controlling for a number of other variables (socio-demographics, family support, whether the parent had another illness, and being prescribed medication in the last year), the significant predictors were *perceived IBD-related health status*, *parenting difficulty*, and the *interaction between family support and parenting difficulty*. Increases in perceived IBD-related health status were associated with decreases in depression and increases in parenting difficulty were associated with increases in depression. In relation to the

interaction, when parenting difficulty was low, family support made very little difference to parental depression. However, when parenting difficulty was high, support from others in bringing up their child/ren greatly reduced parental depression. In other words, the data supports the stress-buffering theory of social support (Underwood, 2000). In addition to this, there is evidence that parenting difficulty was a partial mediator of the relationship between perceived IBD-related health status and depression.

In recent years, researchers have pointed out that it is crucial to take families' social and financial circumstances into account when assessing the impact of parental illness on parenting capacity and children's adjustment, since such factors may have more relevance than their diagnosis or condition (Newman, 2003; Rintala, *et al.*, 2000). It is therefore noteworthy that significant predictors of depression were found *after* controlling for financial difficulties, suggesting psychological distress is not simply the result of poverty.

In summary, the results of the regression analysis on depression are in line with hypotheses developed from the qualitative research as to factors that influence parental distress. However, it is important to bear in mind that the research is cross-sectional and therefore significant results only indicate an association between variables, not that one factor causes another.

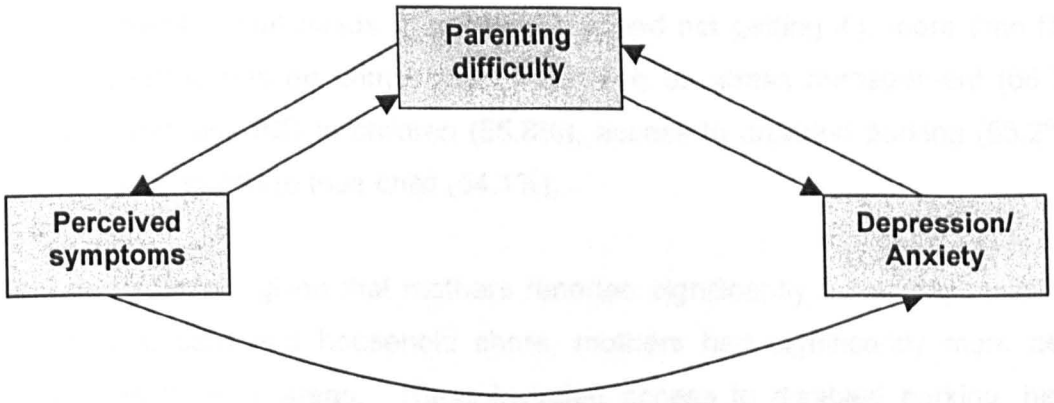
When regression analysis was applied to HADS anxiety data, parents' anxiety was not well explained by the conceptual model. Only 25 per cent of the variance in HADS anxiety scores was explained by variables available from the survey. After controlling for other variables (parent's financial situation, work situation, family support, and whether s/he had another illness), only *perceived IBD-related health status* had a significant effect on anxiety, with decreasing symptoms associated with decreasing anxiety. However, as in the model of parental depression, the direction of effect remains uncertain, and it is equally possible that anxiety leads to deterioration in parent's perception of their health. Clearly the model only goes a small way to explaining anxiety in parents with IBD, and any future research needs to explore other factors. For example, it is worth remembering that steroid therapy may influence mood (Rampton, 1999). Other possibilities include nutrition, with one study of IBD patients finding that levels of state anxiety and depression were significantly higher in under-nourished patients (as assessed by body mass and preservation of fat) (Addolorato *et al.*, 1997).

Regression analysis was also used to examine the relationship between parenting difficulty and the age of a parent's child/ren since both the qualitative research, and previous studies involving parents (Barlow *et al.*, 1999; Hilton, 1996; Grimshaw, 1992; Hilton and Elfert, 1996), suggests parents' difficulties are greatest with pre-school children. The analysis did find a small significant association between the age of the youngest child in the family and parenting difficulty, with increasing child age associated with less difficulty. However, when the data were tested to see if child age *moderated* the effect of the parent's illness on parenting difficulty, no such effect was found. In others words, parents of older children had less difficulty with parenting tasks, irrespective of their health.

It is important to note that the survey failed to support one hypothesis developed as a result of the qualitative research and supported by previous research with parents (Smith and Soliday, 2001; Barlow *et al.*, 1999; Grimshaw, 1992); that parent's sex moderates the impact of parenting difficulty on parent's anxiety/depression. It is possible that this is due to the survey sample, which included only a small proportion of fathers with IBD. In addition, fathers who took part may not be representative of the general population of fathers with IBD, being particularly motivated to take part in the research.

Finally, it should be acknowledged that pathways other than those tested might have an effect on anxiety and depression. As discussed in Chapter 2, there is research evidence to suggest that perceived stress is associated with increases in IBD disease activity, which in turn is associated with increases in anxiety and depression (Searle and Bennett, 2001). Therefore, it is possible that parenting difficulty (a perceived stress) increases symptoms of IBD, which in turn leads to depression/anxiety. Feelings of depression/anxiety may in turn making it more difficult to carry out parenting tasks (see Figure 13 for summary).

Figure 13: Transactional model of the relationship between disease activity, parenting difficulty and depression/anxiety



Parents' support needs

The survey revealed that parents' greatest need was for psychological support. More specifically, parents said they needed advice on stress management (72.1%), and an opportunity to talk to a counsellor about coping with IBD (53.8%). The need for psychological support is not an issue raised in the pre-existing, though admittedly small, body of research on the support needs of parents with an illness/disability. However, the existing research is concerned largely with disabled parents, who might be expected to have different needs from parents with IBD. The findings *do* fit with the large proportion of survey respondents reporting anxiety and depression, and the fact that many parents recognised that their anxiety about the embarrassing nature of IBD symptoms had an impact on family life, limiting their willingness to leave the home. In addition, the high priority given to stress management is not surprising when it is considered that many people with IBD believe that stress plays a role in exacerbating their condition (McColl *et al.*, 2004; Nightingale, 2000; Theis and Boyko, 1994). It also fits with a recent consultation exercise with NACC members who have UC, which found that their main research priority was to find ways in which people could be helped to cope with their illness, including ability to cope with stress (McColl *et al.*, 2004).

Aside from psychological support, the majority of parents (67.4%) had a need for disabled parking in order to be able to get to a toilet quickly. Other support needs endorsed by more than 50% of respondents included information and advice on the effects of IBD on family life (64.3%). Similar to parents with cancer (Barnes, 2000) and PD (Grimshaw, 1992), parents also had a need for help with explaining their condition to their children,

with 59.9% saying they needed a booklet which explains IBD to children and 57.6% that they needed advice on explaining IBD to their child.

The research evidence indicated that on the whole these needs were not being met. When asked about *unmet* needs (i.e. 'Need this and not getting it'), more than fifty per cent of respondents had an unmet need for advice on stress management (65.7%), a booklet which explains IBD to children (55.8%), access to disabled parking (55.2%) and advice on explaining IBD to their child (54.1%).

As might be expected, given that mothers reported significantly more responsibility than fathers for child care and household chore, mothers had significantly more need for support in a number of areas. These included access to disabled parking, help with explaining IBD to their children, an opportunity to talk to a counsellor, time to recover from treatment before being sent home from hospital, help with housework, someone to look after their child while attending hospital on an inpatient or outpatient basis, and information and advice on pregnancy.

When differences according to the age range of children were examined, parents of pre-school aged children had the greatest need for information on the effects of IBD on family life, an opportunity to talk to other parents with IBD, an opportunity for the family to meet other families in a similar situation, information and advice on the effects of IBD on pregnancy, and for someone to look after their child when having hospital appointments. In line with recent research and briefing papers which have highlighted the difficulties disabled parents have transporting their children to and from school (Morris, 2004a; Wates, 1997; Association of Disabled Parents in Norfolk, 1996), a substantial proportion of parents of primary school-aged children (44.6%) had a need for help with this task. Given that many people with IBD find their symptoms are worst in the morning, getting children to school is likely to be particularly problematic.

Clearly there is room for improvement in the support offered to parents. An important issue uncovered by the qualitative research is that parents tended not to discuss their situation with others, preferring instead to 'keep it within the family', with embarrassment about the symptoms of IBD preventing many from disclosing that they had the condition to others. In other words, in some cases lack of support from service providers may be due to them being unaware a parent needs help.

13.4.2 Findings on children

The impact of parental IBD on children

The survey of young people who had a parent with IBD found that they were doing well in many aspects of everyday life. Overall they had an active social life, and were no different from a British community sample in terms of their involvement in organised social activities for young people, how much time they spent with peers, and how often they went to visit a friend in their home. This finding may seem at odds with the fact that organising social activities was rated as one of the tasks parents had most difficult with. However, the qualitative research offers an explanation, with children reporting that although their parent might not be able to take part in social activities, they could still go out with the other parent, relatives, and family friends. Furthermore, the survey of young people was based on 11-16 year olds, who are not as dependent as younger children on their parents organising their social life.

Although the survey findings on young people's social life were generally positive, young people were significantly less likely to have friends to visit them at home than the general population, a finding that fits with the suggestion by some parents in Study 1 that embarrassment about having a 'smelly parent' made it uncomfortable for children to have friends in the house.

The survey suggested children's responsibilities within the home were not particularly onerous. When asked about the type of tasks they were involved with, everyday household tasks were reported most frequently. Just over half (51.4%) of young people had stayed at home to make sure the parent with IBD was alright, but this was a fairly rare occurrence, with most saying they only did this 'sometimes'. When given the opportunity to list any other things they did to help, only a few described tasks directly related to the parent's condition, such as calling an ambulance, talking to doctors, helping the parent to have a drink, or providing emotional support. The majority of 11-16 year olds felt that they did about the same around the home as their peers, and most (82.4%) spent less than three hours a week doing chores. The fact that young people seemed not to be heavily involved in household tasks may seem surprising given that parents reported that domestic chores was the parenting task they had most difficulty with. However, in the qualitative research, children explained that, as in previous research on MS (Blackford, 1995), sometimes chores were simply left until the ill parent was well enough to deal with them. In addition, children said the other parent often took over household tasks. Given that the survey sample consisted predominantly of two-parent households, the later

approach was possible for most families. An attempt was made to test whether the extent to which children got involved in household chores, and their perception of how much they did compared to peers, were associated with whether they lived in a single parent household. Unfortunately, the small number of single parent families involved in the survey prohibited the analysis.

It was rare for survey participants to report disruptions to school attendance because of the parent's illness. One reason may be that young people were not heavily involved with household tasks or caring roles. Furthermore, the survey was based on 11-16 year olds, who are not as reliant as younger children on parents transporting them to and from school. If the survey had included younger children, findings may have been different.

Previous qualitative research has suggested both that parental illness can lead to closer relationship between the parent and child (Lundwall, 2002; Barlow *et al.*, 1999; Wates, 1997; Grimshaw, 1992; le Gallez, 1993; Nelson *et al.*, 1994; Allaire, 1988; Lewis *et al.*, 1985), and to increased strain in the relationship (Deatrick, 1998; Rehm and Cantanzaro, 1998; Hilton and Elfert, 1996; Blackford, 1995; Nelson *et al.*, 1994; Craft, *et al.*, 1993; Grimshaw, 1992). In this research, findings were similar in that both parents and children involved in the qualitative studies reported that parents could be irritable or withdrawn during periods when they were unwell, but some also felt they were closer as a family because of their experiences. While there may be periods of difficulty in the relationship between parent and child, the survey found that overall most young people had a good relationship with their parents, with quarrelling infrequent and talking about things that matter frequent.

In line with previous research (Lundwall, 2002; Smith and Soliday, 2001; Barlow *et al.*, 1999; Thorne *et al.*,1990; Allaire, 1988; Friedlander and Viederman,1982), parents involved with Study 1 felt that a positive consequence of having a parent with an illness was that their children were more caring towards others, particularly those who were unwell. In the survey, this hypothesis was investigated using data from the prosocial sub-scale of the SDQ. This sub-scale includes items on the extent to which a child is 'considerate of other people's feelings', 'shares readily with other children (treats, toys, pencils etc.)', 'helpful if someone is hurt, upset or feeling ill', 'kind to younger children', and 'often volunteers to help other people (parents, teachers, other children), so clearly taps into behaviours parents thought might be effected. Unfortunately, since parent-reported and self-reported SDQ prosocial behaviour scores were not normally distributed, it was not possible to test whether any differences between the survey and a British community

sample (Meltzer *et al.*, 2000) were statistically significant. However, comparison of the scores suggested they were not substantially different.

Despite the fact that many aspects of children's everyday life seemed to be unaffected by their parent having IBD, there was one area of concern. A high proportion of children were experiencing emotional and behavioural difficulties that met the clinical cut off for being a psychiatric case. In the survey of young people aged 11-16 years, 17.6% reported that they were experiencing case difficulties (4.1% definite, 13.5% probable). When parents were asked about their children aged between 4 and 16 years, 30.7% of the children met the clinical cut-off for case level difficulties (18.9% definite; 11.8% probable). As discussed before, such prevalence rates must be treated with caution since screening questionnaires overestimate the number of people with difficulties (Clark and Harrington, 1999). Nevertheless, the findings are worrying since the proportion meeting case criteria are significantly and substantially higher than in a British community sample (Meltzer *et al.*, 2000).

One factor to take into account in reporting these prevalence rates is that a high proportion of children in this sample had a parent with moderate to severe anxiety or depression. Research reviews consistently find that children are adversely affected by their mother's depression (see Goodman and Gotlib, 1999; Cummings and Davies, 1994) and it is possible that the parent's psychological distress may have impacted on child well-being. Bivariate analysis revealed statistically significant associations between parent-reported SDQ total difficulties scores and parental depression ($r= 0.34$, $p<.001$), and anxiety ($r=0.30$, $p<.001$), as well as a significant association between self-reported SDQ total difficulties scores and parental depression ($r=0.32$, $p=.02$).

In addition to this, as suggested by previous research (Najman *et al.*, 2000), anxiety and/or depression may have affected the parent's perception of the child's behaviour, causing them to be overly pessimistic in their responses to the SDQ. Unfortunately, it is not possible to assess how realistic parents' perceptions of their children are since data on children's emotional and behavioural problems were not gathered from other sources (aside from self-report from 11-16 year olds). When the data were checked to assess the level of agreement between parent and self-report, there was a Cohen's Kappa of 0.30 ($p=.010$). In most cases (55/71) they agreed as to whether the young person reached the clinical cut off for caseness (probable and definite). However, in 11 cases the parent rated their child as having case level difficulties when the young person did not. It was less common for young people to report cases level difficulties when the parent did not

(5/11). Whether or not parent-reported prevalence rates are wholly 'accurate', the findings remain worthy of note given that it is the parent's perception of the child that is most likely to lead to the family seeking out help from service providers.

Factors that influence children's emotional and behavioural difficulties

In order to understand which factors influence children's emotional and behavioural difficulties, regression analysis was applied to the survey data. However, these analyses, particularly the analysis of self-reported data, are best described as exploratory since they were based on very small samples of children.

When regression analysis was applied to parent-reported SDQ total difficulties scores, only 33 per cent of the variance in scores could be explained by variables available from the parent's survey. After controlling for other variables (socio-demographics and the parent illness variables) the *child's age, parenting difficulty*, and *whether the child has an illness, health problem or disability,* were significant predictors. In keeping with the qualitative research, increases in child age were associated with a reduction in parent-reported emotional and behavioural difficulties. Both the child having an illness, health problem or disability, and increases in parenting difficulty, were associated with an increase in parent-reported difficulties. Unfortunately, the cross-sectional nature of the study means that the direction of the relationship between these variables remains uncertain, and it is possible that the child's emotional and behavioural difficulties leads to parenting difficulties. This finding differs from research on children who have a parent with cancer (Grant and Compas, 1995; Compas *et al.*, 1994; Howes *et al.*, 1994), in which psychosocial difficulties increase with age. One possible explanation is the fact that, unlike cancer, IBD is not a life-threatening condition. Therefore, while in the cancer situation older children who have a greater understanding of the illness may appraise the parent's illness as highly threatening, when a parent has IBD the development of a better understanding of the illness should result in a reduction in appraisals of threat.

It is worth noting that although, as previously discussed, parental anxiety and depression were significantly associated with parent-reported SDQ total difficulty scores, once the aforementioned variables were entered into the model, parental anxiety and depression were not significant predictors. This is not surprising given that were was a significant association between parenting difficulty and parental anxiety (r=. 36, $p<.001$), and between parenting difficulty and depression (r=. 63, $p<.001$), and suggests that parenting difficulty may mediate the relationship between parental distress and the child's emotional and behavioural difficulties.

When regression analysis was used to identify predictors of self-reported SDQ symptom scores, a much wider range of variables available from the young people's survey were included in the model. Despite this, only 36.5 per cent of the variance in scores was explained by variables available from the survey of parents and young people. After controlling for whether the child has an illness, health problem or disability, only the *frequency of talking to their father*, and *the frequency of arguing with their mother*, were significant predictors. As the frequency with which young people talked to their father about things that matter increased, self-reported SDQ total difficulties scores were reduced. As the frequency with which a young person argued with their mother increased, self-reported SDQ total difficulties scores increased. Since most of the parents with IBD were mothers, this suggests frequency of arguing with the ill parent and talking with the well parent are predictors of children's difficulties. Once again, it is not possible to be certain of the direction of the association between these variables. It is possible that a child having emotional and behavioural difficulties results in increased quarrelling and reduced talking between the parent and child.

Once again, although parental depression was associated with the child's self reported SDQ total difficulties scores, parental depression was not a significant predictor once the aforementioned variables were entered into the model. Given that parental depression (which usually represents maternal depression due to the sex distribution of the sample) was associated with frequency of arguing with mum ($r = -.26$, $p = .046$), it is possible that arguing with Mum mediates the relationship between parental depression and children's emotional and behavioural difficulties.

The later findings runs contrary to parents' expectations. Although participants in Study 1 acknowledged that mothers and fathers with IBD were likely to be irritable due to the condition, they considered it a minor issue for the child compared to the impact of IBD on a parent's ability to care for the child. However, the results do fit with previous research with parents with cancer, which found an association between the quality of the child's relationship with the non-ill parent and the child's psychosocial adjustment (Lewis *et al.*, 1989; Steele *et al.*, 1997a), and with the wider literature on child and adolescent resilience and invulnerability to stress, which finds that nurturing from alternative caregiver is protective in families in which a parent is absent or incapacitated (Werner, 2000). Furthermore, the fact that the regression analysis suggests parenting difficulty is less important than the relationship between the parent and child may reflect the fact that few parents in this study had very severe difficulty with parenting.

A number of elements of the conceptual models outlining predictors of children's emotional and behavioural difficulties were not supported by the regression analyses. First, there was no evidence to support the hypothesis that frequency of hospitalisation was a major determinant of children's adjustment. With hindsight, a more sensitive measure, tapping into whether the child had visited the parent in hospital and, if so, whether they had been distressed by the visit, should have been used.

Second, in the analysis of self-reported difficulties, the child's perception of the severity of the parent's illness, a factor found to predict children's adjustment in previous research on parental illness (Nelson and While, 2002; Compas *et al.*, 1996; Compas *et al.*, 1994), did not emerge as significant predictor. However, it is too early to conclude that this factor is not a predictor of children's adjustment to parental IBD. In this study, similar to Compas and colleagues, the child's perception of illness severity was assessed very simply, using a single item, with four responses options ranging from "not at all serious' to 'very serious'. Further research involving a more sensitive measure may produce different findings.

Third, in the regression analysis of both parent and self-reported emotional and behavioural difficulties, it was hypothesised that social support would have a moderating role, reducing the impact of other factors, such as parenting difficulty, on the child. No such effect was found. However, social support was assessed using a measure of support offered to parents. An effect may have been detected if the social support available directly to young people had been assessed.

Finally, it is possible that the results were affected by the regression analysis being carried out on such small samples (N = 113 for the regression analysis of parent-reported data, N = 38 for the regression analysis of self-reported data), thereby increasing the probability of Type II errors, and reducing the possibility of detecting effects.

Children's support needs

Within the wider literature on parental illness, one of the main issues of concern in relation to supporting children is whether it is beneficial to talk to children about the parent's illness. It was therefore important that this issue be investigated in this research. In Study 1, there was no consensus amongst parents as to whether or not children should be given information about IBD. In Study 2, there was some evidence to suggest that children benefit from information, particularly when a parent is in hospital. Just as reported in Craft's (1993) study of children whose parent was admitted to a medical or cardiac intensive care unit, children said visits to parents in hospital reduced worry, and medical

equipment became less frightening when its purpose was explained to them. The survey produced only limited evidence to support the hypothesis that providing information is beneficial. Data on the extent to which children had talked to their parent about IBD was only available for the 11-16 year olds who had taken part in the young people's survey. However, this variable was assessed very crudely, using a single item with three response options. This, combined with the small sample of children, meant there was little variation in scores. It was therefore not surprising that, although there was a significant association between the extent to which young people had spoken to their parents about their illness and self-reported emotional and behavioural difficulties, this was small ($r=-.27$; $p=.05$). As a result, the variable was not selected for inclusion in the regression analysis. Research involving a larger sample of children, and a more thorough assessment of communication within the family, is needed before any firm conclusions can be drawn about whether providing children with information about the parent's illness affects their well-being. Whether or not there are benefits in terms of psychological well-being to providing information, the survey of 11-16 year olds suggests that young people are in favour of being given information, with 81.7% saying they had a need for information and advice about their parent's health. In most cases, young people had access to sufficient information, but over a third (36.6%) had an unmet need for information and advice.

Young people had few other support needs. Although 50.7% of survey respondents said they needed someone to talk to about their parent's health, in most cases this need was met. Just 14.1% had an *unmet* need for someone to talk to. Only a small proportion felt they had a need to meet other young people whose parent was unwell, or had a need for help around the home (17.1% and 19.7% respectively). The fact that so few wanted to meet young people whose parent is unwell is noteworthy given that researchers investigating other conditions have proposed that such support might be useful (Grimshaw, 1992; Rosenfield, 1983). However, these recommendations are based on suggestions by parents and young people made during the course of qualitative research. It may be that if these researchers had gone on to investigate the extent of demand for such support, they too would have found that the need for such interventions is not high. Finally, in relation to all of the findings on young people's support needs, it is important to bear in mind that the findings only represent the views of 11-16 year olds. The needs of younger children may differ. In particular, given that the qualitative research suggests younger children have a more limited understanding of IBD, their need for information and advice may be greater.

13.5 Reflections On Theoretical Frameworks

This research was guided by primarily by the transactional model of stress and coping (Lazarus, 1999; Lazarus and Folkman, 1984), supplemented by the family-systems illness model (Rolland, 1999; 1984), and the resource-based approach to intervention (Dunst *et al.* 1988). In this section, two issues are discussed: the usefulness of adopting these theories and the extent to which the findings fit with, and add to, the frameworks.

13.5.1 Reflections on the usefulness of the frameworks

As discussed in Chapter 1, by adopting the transactional model of stress and coping framework as the primary theoretical framework, the research focused on the experiences and needs of individuals, namely parents with IBD and their children, rather than the family unit. In the qualitative research this meant that parents and children were interviewed separately, which proved advantageous for two reasons. First, participants spoke about issues that they may not have felt comfortable discussing together. For example, parents talked about the symptoms of IBD, the extent to which they sometimes struggled with everyday life, feelings of anxiety and depression, uncertainty as to whether their child's complaints of gastrointestinal problems were genuine, and worries about their child inheriting IBD. All these issues are unlikely to have been discussed in such depth if parents had taken part in a joint interview with their children since many spoke of how important it was to them not to worry their children, and some limited the information they gave their children about IBD. The qualitative research with children also produced data that might not have been elicited if children had been asked about their experiences in the presence of parents. For example, the fact that children sometimes kept their feelings of upset, worry and anger hidden from their parents, and that some felt guilty about their parent's condition, believing it was linked to stress and the parent taking on more responsibility for childcare than they could manage.

A second advantage of interviewing parents and children individually, rather than carrying out family interviews, was that the research revealed differences in how parents and children perceived the effects of IBD on family life, and in their support needs. For example, as discussed above in section 13.3, although parents were upset by their inability to take part in family social activities, many children, particularly adolescents, were not greatly concerned about the matter. In relation to support needs, while parents wanted help in a wide range of areas, children reported that they had little need for support, aside from being given information about their parent's condition.

The theoretical frameworks also influenced the nature of the research questions posed, particularly during the qualitative phase. Both the transactional theory of stress and coping and the family-systems illness model resulted in efforts to investigate how parents and children perceive IBD, and when it is problematic, why this is the case. Understanding such matters was an essential to the development of the recommendations on how best to support parents with IBD and their children, which follow later in this discussion. In addition, the adoption of the transactional model of stress and coping meant considering the way people coped with stressors. This was useful in that, instead of the research focusing solely on the extent to which parents with IBD and their children need help, it is acknowledged that, in many cases, parents and children are successfully managing many of the difficulties they encounter.

The resource-based approach to intervention highlighted the importance of asking parents with IBD and their children for their views on how they might best be supported. Without this model it might have been tempting to base recommendations solely on data about parents' and children's difficulties, only to find at a later date that there is little demand for the recommended interventions. For example, the research found that emotional and behavioural difficulties were more prevalent amongst children than in a British community sample. Based on this information, it would be reasonable to suggest the development of psychosocial interventions, such as those developed for children who have a parent with cancer (see Chapter 4, section 4.3.2). However, in this research, when parents and children were asked about the types of support they wanted, although there was a demand for psychological support for parents, there was no such demand for children.

Despite the advantages described above, there was one major difficulty with adopting Lazarus and Folkman's transactional approach to stress and coping. Within this framework it is accepted that there are likely to be extensive mediational and reciprocal feedback loops within the stress and coping process. Unfortunately, as warned by Lazarus (1999), it is difficult to test such complex models. In this research, relatively simple linear models of factors that predict parent's psychological distress, and children's emotional and behavioural difficulties, were developed and tested using regression analysis. On reflecting on the findings, it is acknowledged that pathways other than those tested are possible (see sections 13.3.1 and 13.3.2 above). In order to better understand the relationship between the various variables implicated in parent's psychological distress, and children's emotional and behavioural difficulties, it would be useful to carry out a longitudinal study, with a sample sufficiently large to allow extensive statistical

testing. Unfortunately, such a study could not be accommodated within the financial and time constraints of this thesis.

13.5.2 How the findings fit with the theoretical frameworks

In Chapter 3, a number of predictions were made about the impact of IBD on parents and their children based on the three theoretical frameworks. Below the extent to which the findings fit with these predictions, and are generally in line with the frameworks, are discussed in turn.

The transactional theory of stress and coping

As might be expected, symptoms of IBD made parenting more difficult for individuals. However, the transactional theory of stress and coping suggests that the extent to which this is 'threatening' or 'challenging' to a person will vary according to whether being a 'good parent' is an important goal to the individual. In line with this prediction, the qualitative research found that parenting was a more pertinent issue to mothers than to fathers, with fathers able to hand over responsibility for childcare during times of illness, and, as a result, mothers spoke frequently about feelings of depression brought about by difficulty with the parenting role. In contrast, when fathers spoke about negative feelings, they were often related to having to give up employment. Based on these findings, it was hypothesised that the parent's sex moderates the impact of parenting difficulty on parent's psychological distress. However, the regression analysis revealed no interaction effect. It is possible that this negative finding reflects the fact that fathers who took part in this study placed particular importance on their role as parent. Further research involving different samples, and including an assessment of how important involvement in childcare is to the individual, is needed before conclusions can be drawn as to whether there are differences between mothers and fathers in how they respond to parenting difficulty, and if so, whether this is due to the value place upon being a parent.

The transactional theory of stress and coping also suggests that when resources for coping are limited, threatening situations are more likely to lead to distress. In keeping with this, the regression analysis of survey data found that when social support was limited, difficulty carrying out parenting tasks was more problematic for parents, leading to increased feelings of depression.

In relation to children, as predicted, the qualitative research suggested that older children appraised the parent's IBD as less threatening than younger children, due largely to

having a better understanding of the condition, but also because they were less reliant on their parents for their social life. It is therefore not surprising that the quantitative research found age was a significant predictor of children's emotional and behavioural difficulties as reported by parents, with older children less likely to have difficulties. In addition, in keeping with the transactional theory, the regression analysis found that when young people had the resource of a good relationship with the well parent, in which they talked frequently, they were less likely to report emotional and behavioural difficulties.

The family systems-illness model

The family systems-illness model 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 (Rolland, 1999). As discussed before, the findings of the qualitative research were in line with this, highlighting the considerable impact that embarrassment about the symptoms of IBD can have both on the individual, and on family life, so that even when they were symptom free, quality of life could be impaired because parents were unwilling to risk planning or taking part in social activities. In addition, the research indicated that social stigma can also affect other members of the family, with the qualitative research suggesting that embarrassment about having a 'smelly' parent reduced the child's willingness to have visitors in their home, and the survey of young people confirming they were less likely to have friends visit their home than is reported in community samples. Finally, as predicted due to the episodic course of the condition, there was little evidence of role reallocation.

The family-systems illness also model suggests that the demands an illness places on a family vary according to the family life cycle, with greatest difficulty experienced when a chronic illness develops during the child-rearing years. In keeping with this, both the qualitative research and the regression analysis of survey data found that parents with IBD experience more difficulty with parenting younger children. However, in the regression analysis, illness severity did not *interact* with the child's age. In others words, severe illness did not create any more difficulty for parents with IBD who had young children than it did for parents of older children.

A number of factors may have contributed to this failure to detect an interaction effect. First, the illness variables used in this analysis - the SIBDQ, whether prescribed medication in the last year, and presence of another illness, may not have been good enough indicators of illness severity. The SIBDQ asks specifically about symptoms over

the previous two weeks. As discussed previously, since IBD is such a fluctuating condition, this means responses to the measure may not be representative of experiences over longer time frames. Being prescribed medication over the previous year is unlikely to be a useful way of discriminating between those who do and do not have severe IBD since most survey respondents (89.8%) were prescribed medication. In addition, simply because a parent had an illness other than IBD does not necessarily mean that they were more unwell. Another explanation for the failure to detect an interaction effect may simply be that the study was not sufficiently powerful, being based on samples of between 147 and 151 parents. In summary, further research is needed before any firm conclusions can be drawn about whether illness severity interacts with child's age to predict parenting difficulty.

The resource-based approach to intervention

The resource-based approach to intervention warns that availability of support from intrafamily and extrafamily resources is not sufficient for families to utilize it. The qualitative research with parents found that a number of factors highlighted by the model, such as response costs, dependability, and indebtedness, did act as a barrier to parents with IBD accepting help from others.

13.6 Recommendations On Supporting Parents With IBD

Overall the findings from the research, particularly the survey, indicate that, in this sample at least, parents' main need is for support with psychological stress and distress. First, parents' response to the HADS suggested that substantial proportions are at risk of having case level anxiety and depression. Secondly, parents themselves rated advice on stress management as their highest priority in relation to support, with 72.1% reporting that they had a need for this type of intervention, and 65.7% indicating that this need was unmet. A further 53.8% reported needing an opportunity talk to a counsellor about IBD, and in 45.6% of cases this need was unmet. Service providers can intervene at two levels. First, to prevent psychological distress from arising. Second, to help those who are already feeling anxious or depressed. Drawing on the thesis findings, and existing research, the way in which service providers can help with these tasks is discussed in further depth below.

13.6.1 Helping parents to avoid feelings of stress and distress

The main purpose of applying regression analysis to the survey data was to try to understand which factors influence the level of anxiety and depression experienced by parents, and so identify ways in which service providers can intervene to reduce the likelihood of parents becoming distressed. This analysis identified a number of significant predictors of anxiety and depression, including perceived IBD-related health status and parenting difficulty, which deserve consideration.

Improving perceived health status

Given that parents' perceived IBD-related health status was a significant predictor of both anxiety and depression, it is *possible* that by supporting parents in ways that improve health, clinicians may in turn reduce psychological distress. Needless to say, health professionals already work hard at alleviating patients' symptoms and improving their quality of life. However, the research points to areas where they could provide further assistance.

First, for some patients with UC it may be appropriate to consider having an ileostomy to reduce symptoms and improve quality of life. It was clear from Study 1 that people who had an ileostomy found it very beneficial in terms of coping with family life. However, it was also apparent that opting to have an ileostomy was a difficult decision to take, and that parents valued being given the opportunity to meet others who had gone through the process. Such findings support the setting up of a 'buddy system', as adopted in some centres for the treatment of IBD, in which people who have received an ileostomy or undergone pelvic pouch surgery are asked to volunteer to be matched with new patients who are candidates for the surgery (Maunder and Esplen, 1999).

Second, parents spoke of how parenting responsibilities may hinder recovery from flare-ups and surgery. It is therefore important that health professionals discuss home circumstances with the patient, encouraging them to seek support from family and friends. Where there is likely to be little opportunity for rest at home, one possibility is parents' suggestion that they be given time to recover from treatment before being sent home from hospital. Other possibilities include trying to secure respite services, domiciliary help, or childcare while the parent convalesces. Unfortunately, obtaining such help is unlikely to be straightforward. This issue is discussed further in the next section of the discussion.

Clearly the control of symptoms is not the sole responsibility of the health professional; the patient also has a role to play. As Barlow (2002) has pointed out, the reality of chronic disease is that over time responsibility for day to day disease management gradually shifts from the healthcare professional to the individual. The question than is to what extent can parents be enabled to manage their own condition effectively? Unfortunately, those who have reviewed psychological interventions aimed at improving the health status and quality of life of patients with IBD have concluded that such interventions are not effective (Levenstein, 2002; Searle and Bennett, 2001; Schwarz and Blanchard, 1990). Levenstein (2002) goes as far as to encourage clinicians not to waste time, resources and energy on psychologically orientated therapies unless there is a clear indication that psychological factors play a role in the course of an individual's disease. Since these reviews were undertaken, further interventions aimed at improving self-reported health status, including the provision of educational materials on IBD (Borgaonkar *et al.*, 2002; Kennedy and Rogers, 2002), and self-management package for patients with UC (McColl *et al.*, 2004), have been trialled. Despite the fact that participants often speak positively of such interventions, all have proved unsuccessful in improving perceived health status. It is worth bearing in mind that the effectiveness of such interventions are judged on changes in quality of life measures. With a condition such as IBD, a sudden flare up in the patient's condition can have a very strong effect on scores on such measures, resulting in a negative finding, despite the fact that a psychological intervention is not expected to prevent such flare ups. Results might also have been negatively influenced by difficulties obtaining a sample sufficiently large to detect the effects of the intervention. Until research demonstrates that such interventions improve patients' quality of life, and are cost-effective, patients are unlikely to be routinely offered self-management programmes, even if they consider them to be worthwhile.

Reducing parenting difficulty

The need for parents to receive help with parenting tasks when they are convalescing has already been discussed. However, there is a second reason why it may be important to offer people with IBD help in their parenting role; the regression analysis suggested parenting difficulty partially mediates the association between perceived IBD-related health status and depression. In other words, by supporting people with parenting it may be possible to reduce depression.

Unfortunately, it has been suggested that many professionals involved with chronically ill patients are reluctant to discuss parenting issues for fear of distressing their patient (Altschuler and Dale,1999). In Study 1, a number of parents said they did not always tell

others when they were experiencing difficulties, and those who had received support from midwives and health visitors had only done so because the professional had noticed they needed help. Therefore professionals do need to be proactive in checking whether parents want assistance. 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. To help with this task, it might be useful if a brief screening questionnaire was developed.

In the prediction of depression, social support was found to interact with parenting difficulty so that, even if parents were experiencing a lot of difficulty with parenting tasks, if support was available to them, the level of depression was greatly reduced. Therefore, when a parent is experiencing difficulties, one of the first steps may be to explore what resources they have available to them for managing the situation within their informal network of friends and family.

Securing help from partners depends on them understanding and accepting IBD and its impact on family life. As parents in Study 1 pointed out, it cannot be assumed partners will respond in this way. In the survey a small, but noteworthy, proportion of parents felt their partner had an unmet need for information and advice on IBD (20.6%) and someone to talk to about them having IBD (23.8%). 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. Again, this may be a role that can be undertaken by specialist nurses.

Many parents who have an illness or disability find it difficult to ask for help from informal sources of support due to not wanting to be a burden to others (Fitch, *et al.*, 1999; Wates, 1997) or jeopardise friendships (Allaire, 1988). For parents with IBD the situation may be further complicated by the fact that many find it difficult to discuss IBD due to the social stigma associated with symptoms. Therefore, an important task for health professionals regularly in contact with parents who have IBD is to help them overcome any feelings of embarrassment. Parents may also benefit from resources to help them explain the condition to others, such as the brief guide on IBD produced by NACC.

If the support parents need is not available from family, friends and the school community, parents may want to consider accessing help, such as domiciliary care, child day care, adult respite, and transport, from social services and local education authorities. If they

are offered help, it seems likely that, in line with research with disabled parents, they will favour direct payments (cash in lieu of services) so that they have some control over who cares for their children and when help is provided (Olson and Tyers, 2004). However, such help may not easily be obtained. When the Social Services Inspectorate investigated support for disabled adults in their parenting role in 2000, there was considerable variation between councils in the number and type of services provided to disabled parents. Parents also had difficulty accessing the services due to lack of information on what was available to them and the eligibility criteria, and the fact that neither adult or child services saw it as their responsibility to support parents in their parenting role (Goodinge, 2000). Since this report was published, the needs of disabled parents have been highlighted by initiatives such as the JRF task force on 'Supporting disabled adults in their parenting role', and there is some evidence of a growing resolve within social services to support disabled parents (Wates, 2002). Unfortunately, despite these improvements, accessing services may be particularly difficult for parents with IBD.

First, parents with IBD are unlikely to be aware that support is available since they are not generally in contact with social services. Second, in order to access support, there are two main routes; through their child being assessed as 'in need' under the Children Act 1989, or through community care legislation. For many parents, there is considerable stigma to a child being assessed as 'in need' since it is associated with 'child protection' procedures (Morris, 2004b; 2003) and parents may not want to go through this process. Under the alternative route – through community care legislation, in order to be eligible for support a parent has to be legally defined as a 'disabled person'. This is problematic for people with IBD for a number of reasons. First, since service providers often have very little knowledge of IBD, they may not understand how it is possible for a person with the condition to be disabled. Second, it is known that many people with IBD do not apply for disability benefits because they do not perceive themselves as disabled (Donnison and Whitehead, 2004). Third, even if a person does apply for help, in order to prove they are disabled they are likely to have to disclose detailed information on the very aspects of their condition they find so difficult to discuss with others. Furthermore, accessing mainstream services can also be complicated by the fluctuating nature of IBD, which makes it hard to predict when support will be needed. Given these barriers, parents may benefit from assistance in seeking help from social services and Local Education Authorities. NACC already provide written guidance, and a telephone support line, to help people with IBD making claims for Disability Living Allowance. They also encourage people to use their telephone counselling service to talk over any emotional difficulties caused by the process. It would be useful if a similar service could be developed to assist

in obtaining support with parenting. This might include providing information on the services available to people in their parenting role, assistance with applying for help, and raising understanding and awareness of IBD amongst service providers.

13.6.2 Alleviating stress and distress

In situations where parents are already feeling distressed due to IBD, practitioners may need to offer a psychological intervention, and it has been suggested that stress management, relaxation training, self-hypnosis, and meditation training may all be useful to people with IBD (Maunder and Esplen, 1999). Unfortunately, there is limited research evidence on the effectiveness of such interventions in reducing distress in people with IBD, and studies that have produced positive findings are methodologically flawed. For example, in one of the earliest studies to suggest that stress-management might be helpful, 14 patients with IBD received four sessions in which they were given a massage and taught deep abdominal breathing techniques (Joachim, 1983). At follow up, they reported increased ability to sleep, calm themselves, and to control pain. Unfortunately, no control group was included, and standardised measures were not used to assess change over time.

Milne *et al.*, (1986) carried out a randomised control trial, in which 40 patients attended a series of six classes, lasting three hours each, on stress management. The control group received no intervention. At four, eight and twelve month follow up, the intervention group showed significant improvements on the Crohn's Disease Activity Index, and the IBD Stress Index, whereas the control group did not. Unfortunately, the control and intervention group were not matched for symptom severity, and the intervention group had more active disease prior to treatment.

Schwarz and Blanchard (1991) carried out a small-scale randomised control trial (treatment group included just 11 people) of a behavioural treatment package, which included IBD education, progressive muscle relaxation, thermal biofeedback, and training in the use of cognitive coping strategies. The intervention was on an individual basis and ran over eight weeks. For the first four weeks, patients attended a one hour session twice a week. During the final four weeks, they attended a session just once a week. In addition, patients were encouraged to practice relaxation and biofeedback techniques on a daily basis. Those who received the intervention perceived themselves as better able to cope with IBD-related stress, reported less IBD-related stress and experienced less depression and anxiety. However, since the majority of those who received the

intervention had CD, and were more distressed at baseline, the findings may represent pre-treatment differences between participants. It is also worth noting that participants in this study were people who had contacted a centre for stress and anxiety disorders for help, so are not representative of the general IBD population.

More recently in the UK, the 'Challenge of Change' stress management programme was delivered, via a nurse-led counselling service, to IBD patients with mildly active disease attending a gastroenterology clinic (Smith *et al.*, 2002). The intervention aimed to teach patients to detach themselves mentally from the anxieties surrounding their diagnosis. In addition, patients were provided with booklets and educational videos on IBD, access to a nurse counsellor, and were encouraged to contact a patient support group. Improvements in mental health, as assessed by the SF-36, were found in patients with CD at six months, but unfortunately they were not sustained at 12 months. However, it is important to bear in mind that although the study was based on a larger sample than most (100 IBD patients, 28 patients with psoriatic arthritis, and '50' healthy controls), the investigators acknowledge the sample size was not large enough to detect the effect sizes observed. It is also possible that patients would have benefited from more intensive support; patients received a mean of just 3.25 consultations with the nurse counsellor over a one year period. Furthermore, IBD patients had HADS depression scores within the normal range. Results may have been different if the interventions had been targeted at individuals in greater need of psychological support.

Finally, in an uncontrolled study, 28 patients with UC or CD were enrolled in a 12 weekly course of cognitive-behavioural therapy, which involved 90 minute group sessions per week aimed at reducing psychological distress (Mussell *et al.*, 2003). Most participants were in remission when recruited and, on average, their symptoms of psychological distress were not in the clinical range. Each session covered psycho-education about IBD and the role of cognitions and emotions in generating distress, training in adaptive coping strategies for disease-related and everyday distress, and progressive muscle relaxation. Following the course, top up sessions were offered at three month intervals. Assessments at baseline, and three, six and twelve month follow up revealed that depressive symptoms and depressive coping styles decreased over time. However, this effect was gender-related, with improvements in women only. For participants with UC, disease related concerns were also significantly reduced at three month follow up.

Clearly the aforementioned studies suffer from a number of methodological problems, including small sample sizes, lack of control groups, or control groups which are not

matched to the intervention group. Until more rigorous research is carried out, and the effectiveness of interventions firmly established, psychological support is unlikely to be provided within mainstream gastroenterology services. If any further interventions studies are carried out, investigators should note that this thesis, and other research (McColl *et al.*, 2004; Joachim, 1994), suggests many people with IBD find it difficult to attend groups.

Given this situation is worth considering what the gastroenterology team can do within existing services to reduce patients' distress. Drossman (1988) encourages gastroenterologists to take on a therapeutic role, in which the patient is helped to learn about the illness, the way the individual responds to the illness is acknowledged, and the family is involved in treatment decisions. The evidence from this research suggests that such an approach would be welcomed by patients, with participants in Study 1 speaking positively about staff who took a holistic approach to their treatment, helping them to prepare for important family events and giving consideration to their family circumstances when arranging treatment. It would also be helpful if the gastroenterology team could assist patients who feel they might benefit from help with stress management, and counselling, in accessing services that are already available within the NHS, or through voluntary organisations. In particular, it should be noted that NACC provide a telephone counselling service, which is freely available to people with IBD.

13.7 Recommendations On Supporting Children

Data from the survey of young people suggested that in many areas of life, including social life with peers, school attendance, responsibilities within the home, and relationships with parents, young people were doing well, and do not need help from service providers. The circumstances of younger children are less clear since the survey did not collect data from this age group. However, one aspect of the research findings on children of all ages is of concern. Based on both parent and self-report data, the prevalence of emotional and behavioural difficulties amongst children is higher than found within the general population.

Results of the regression analysis predicting such difficulties, though exploratory because of the small sample size, point to a number of ways in which service providers may help to prevent children from developing such difficulties. First, the regression analysis of self-reported difficulties found that increases in the frequency of talking to father, and reductions in arguing with mothers, were associated with reductions in children's

difficulties. As discussed before, it is impossible to be certain of the direction of the association between children's adjustment and relationships with parents. However, assuming that relationships with parents impact on the level of emotional and behavioural difficulties children experience, since children involved in the qualitative research explained that parents became cross, bad tempered, and withdrawn during periods when unwell, efforts to alleviate symptoms of IBD may in turn have a positive affect on the child. Furthermore, interventions discussed previously, aimed at reducing parents' stress and distress, are also likely to improve the relationship between the parent and child, and so in turn help the child.

In relation to the regression analysis of parent-reported difficulties, first, since parenting difficulty was a significant predictor of parent-reported emotional and behavioural difficulties, it is possible that by helping parents with their parenting responsibilities service providers will in turn be helping their children. The child's age was also a significant predictor of parent-reported difficulties, with difficulties decreasing as the child's age increased. The qualitative research with parents and children suggested older children were less worried about their parent because they had a better understanding of IBD, including the fact that it is not generally a life-threatening condition. If this is a reason for age-related differences in outcomes for children, it suggests a need to provide children with sufficient information about the parent's health to alleviate unwarranted worries and fears. Research from both the qualitative and quantitative research indicates that parents would welcome support in this area, with both advice on explaining IBD to children and a booklet written for children given high priority when parents support needs were rank ordered. Furthermore, the survey of young people found that, of all the types of support suggested to young people, information and advice about the parent's health was the most popular.

The qualitative research provided further evidence on the type of information children want, with respondent's speaking of a need for answers to the following questions:

- What is happening to their parent?
- Why are they unwell?
- Why do they need to go to hospital?
- What is the best way to behave around a parent who is unwell?

Evidence regarding the issues that young people worry about also suggests they would benefit from advice on the following:

- How likely is it that someone will inherit IBD from their parent?
- How likely is a parent to die from IBD?
- What happens during surgery?
- Why are they having specific treatments/medical interventions?
- How soon is Mum/Dad expected to return home from hospital?

From the parent's point of view, it would be useful if service providers offered children information on aspects of IBD 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).

If, as suggested by parents, information is provided through a book, care is needed with the content. The impact of IBD on individuals and the treatments people receive is variable. If parents are to avoid giving irrelevant and potentially alarming information to their children, it is important that information is available in sections focussed on specific topics. Parents can then pass on information appropriate to their situation.

Whatever the format of a book, it will not be able to answer the many questions young people have which are specific to their family's situation. Some young people may be able to obtain such information from their parents, but it was clear from the study that many do not wish to discuss such matters with family for fear of upset or embarrassment. This suggests that it would be very helpful for there to be someone outside the family for young people to talk to. Since this person needs to be both easily accessible to young people, and knowledgeable about IBD, it might be a role that gastroenterology nurse specialists could consider taking on. However, as gastroenterology nurses are unlikely to have the training and experience for this task, it would be wise for them to collaborate with colleagues who do. For example, it has been pointed out that paediatric nurses are in an ideal position to support children who have a parent with a chronic illness, particularly in relation to visiting their parent in hospital, since they have knowledge of child development, and how children respond to illness and the hospital environment (Winch, 2001). Finally, in whatever form information is provided, its impact on the child must be thoroughly evaluated. Randomised controlled trials in which adults with IBD have been given written information on IBD have produced mixed results, with some showing no

impact on the patient (Kennedy *et al.*, 2003), and others finding negative effects on quality of life in the short term (Borkoankar *et al.*, 2002).

13.8 Changes In The Researcher's View Of The Research

In Chapter 1 of this thesis, it was suggested that a reflexive position would be taken, acknowledging how the researcher's own position and interests has shaped the research process. As stated previously, at the outset I was an 'outsider' to the world of parents with IBD and their children. However, during the four years it has taken to complete the research this position has changed somewhat. First, the process of carrying out the research, including recruiting and meeting with parent and child advisors to the research, drew me in to the world of parents with IBD and their children. This involvement with people with IBD has made me conscious of how personal the issues in this thesis are to many people with the condition, and the extent to which many parents are striving to do their best for their children, despite the difficulties they encounter. As a result, instead of guarding against the desire to search for problems as suggested in Chapter 1, there was a need to guard against underplaying some of the negative effects to emerge from the research. The writing of researchers concerned with disability rights (Wates, 1997; Morris, 1996), who have pointed out that in order to secure appropriate support for parents it is necessary to acknowledge the difficulties they experience, were very helpful in this regard.

In addition to these experiences, there were a number of changes to my personal circumstances during the course of the research, including becoming a parent and my husband being a diagnosed with a chronic illness, which altered my outlook somewhat. These events did not affect the research design or methods in any way since the events in question did not occur until after data collection. However, it has made me conscious that the research provides a rather narrow view of respondents' lives. Inevitably, in a study that sets out to explore the impact of IBD on parents and children, the parent's illness takes centre stage. In reality, the parent's condition may be one of many factors in a person's life that determine the way in which they parent, their well-being, and the well-being of their children. As Arendell (1997) has pointed out, the challenges confronted by child-rearing parents are vast, including economic stress and poverty, the isolation of individual family units, demands of the work place, and the availability of good quality childcare, to name but a few. In the regression analysis of predictors and parents and children's psychological distress, an attempt was made to take account of other factors

such as socio-demographic circumstances and family support. However, the assumption is still that the main stressor in an individual's life is IBD. In fact, there may be many other events in a person's life that have a greater impact on the individual. It is therefore perhaps not surprising that the regression analysis was only able to explain a proportion of the variance in parents' and children's psychological distress.

13.9 Conclusions

Due to the pain, fatigue, and nausea caused by IBD, and the social stigma associated with symptoms such as incontinence and diarrhoea, IBD has the potential to make the task of parenting more taxing for individuals. In particular, parents have difficulty with domestic chores, providing for the child's financial needs, and organising and taking part in social activities with the family. Such difficulties can lead to feelings of distress, specifically depression, particularly when parents have limited support from family, friends, and professionals. These issues are not widely recognised or dealt with by service providers and, if as prevalent within the wider population of parents with IBD as suggested by the survey, this is a serious omission. Despite the difficulties parents experience, their children, at least in the adolescent years, appear to be largely unaffected in terms of their social life with peers, domestic responsibilities, school attendance, and relationships with parents. However, they may experience more emotional and behavioural difficulties than expected for their age range. Preliminary research aimed at identifying factors that influence children's difficulties suggests experiences vary according to the child's age, whether the child has an illness or disability, parenting difficulties, and the child's relationship with their parents. In line with these findings, and parents' own priorities for help in managing stress and distress, parents can best be supported by medical interventions to prevent a flare up of the condition, assistance with childcare and domestic responsibilities, and psychological support, possibly in the form of stress management and an opportunity to talk to a counsellor about the condition. Such interventions may in turn reduce the likelihood of their children developing emotional and behavioural difficulties. In addition, both parents and young people would value the provision of age-appropriate information for children on IBD and the treatment their parent is undergoing.