

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

Volume II of II

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Table of contents – Volume II

List of abbreviations	270
Glossary.....	271
References.....	273
Appendices.....	295

List of abbreviations

5-ASA	5 aminosalicylic acid
BHPS	British Household Panel survey
CD	Crohn's disease
CT scans	Computerised tomography scans
FSS	Family Support Scale
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health-related quality of life
IBD	Inflammatory bowel disease
IBDQ	Inflammatory Bowel Disease Questionnaire
KD	Kidney disease
MREC	Multi-Centre Research Ethics Committee
MS	Multiple sclerosis
NACC	National Association of Colitis and Crohn's Disease
NS-SEC	National Statistics Socio-Economic Classification
PD	Parkinson's disease
RA	Rheumatoid arthritis
RD	Rheumatic disease
RFIPC	Rating Form of IBD Patient Concerns
SIBDQ	Short Inflammatory Bowel Disease Questionnaire
SC	Social Class based on Occupation
SCI	Spinal cord injury
SDQ	Strengths and Difficulties Questionnaire
SEG	Socio-Economic Groups
SPRU	Social Policy Research Unit
PTI	Parenting Task Index
UC	Ulcerative colitis

Glossary

Colonoscopy

Examination of the entire colon using an instrument similar to that used for fibersigmoidoscopy, but the colonoscope is 1.6 meters in length.

Continent ileostomy

An ileostomy technique that aims to provide continence without the need for an appliance. The end 45 centimetres of ileum is used to fashion a pouch reservoir, which includes a valve to obstruct faecal flow. The patient evacuates the valve at his or her convenience by inserting a catheter into the valve 5 to 6 times a day.

Crohn's colitis

Crohn's disease confined to the colon.

Esophagogastroduodenoscopy

This involves the insertion of a fiberoptic gastroscope into the throat. The instrument is passed into the oesophagus to investigate the upper areas of the gut.

Fibersigmoidoscopy

The insertion of the fibersigmoidoscope into the rectum, until it reaches its full length (60 centimetres), enabling examination of the colon.

Fistula

A channel through the wall of the intestine.

Hepatitis

Inflammation of the liver caused by viruses, toxic substances or immunological abnormalities.

Hypersensitivity reaction

Abnormal response to the presence of a particular antigen, which may cause a variety of tissue reactions ranging from serum sickness to an allergy (such as hay fever) or, at the severest, anaphylactic shock.

Ileal pouch

A reservoir made from loops of ileum to replace a surgically removed rectum, avoiding the need for a permanent ileostomy.

Ileorectal anastomosis

After removal of the colon, the terminal ileum is joined to the rectum.

Ileostomy

Surgical operation in which the ileum is brought through the abdominal wall to create an artificial opening (stoma) through which the intestinal contents can discharge, thus bypassing the colon.

Leucopenia

A reduction in the number of white blood cells (leucocytes) in the blood.

Microscopic colitis

Chronic, watery diarrhea, of obscure or unknown cause. Responds to steroids and 5-ASA and, as a result, some consider it a variant of IBD.

Pancreatitis

Inflammation of the pancreas.

Perianal Crohn's

Crohn's disease in the area of the anus, which usually takes the form of fistula, with or without one or more abscesses.

Proctitis

Features of UC confined to the anorectum. The condition follows a chronic, relapsing course similar to that of UC, but there are seldom systemic features such as weight loss, fever, or anaemia.

Rigid sigmoidoscopy

Endoscopic procedure involving examination of the first 15 centimetres of the rectum.

Systemic symptoms

Symptoms affecting the body as a whole, rather than individual organs.

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Appendices

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Appendix 1

Search strategy for literature review

Search strategy for literature review

Electronic searches

The following databases were searched

ASSIA Plus - 1987 -2002

Cinahl 1982-2002

Medline 1980-2002

PsychINFO 1887-2002

Sociological Abstracts 1963-2002

The search strategy consisted of the following keywords and combination of key words:

Parent*

Mother* or father*

Illness* or disability*

1 and 3

2 and 3

4 or 5

Use of such general terms results in good sensitivity, though specificity is poor; an appropriate strategy for a general review of the literature. Searches were restricted to English language papers since there were no resources to do otherwise.

In addition to the search described above, BIDS ISI Social Science Citation Index was used to search for the citation of key review papers.

Scanning reference lists

The reference lists in all identified articles were scanned for further relevant papers. This task began with review papers, followed by articles describing primary studies.

Hand searching journals

In order to ensure recent publications were not omitted, the following key journals were hand searched between 2000 and December 2002.

Child: Care, health and development

Clinical Psychology Review

Disability and Society

Disability, Pregnancy and Parenthood International

Health Psychology

Journal of Abnormal Psychology

Journal of Consulting and Clinical Psychology

The Journal of Child Psychology and Psychiatry

Grey Literature

In order to include research published by voluntary organisations, rather than by academic publishers, the websites for the following organisations were scanned for completed and ongoing research: Disabled Parents Network, Joseph Rowntree Foundation, National Children's Bureau and National Children's Home.

Ongoing research

In order to identify studies which are ongoing, or for which there are no published data, the National Research Register was searched. In addition, websites describing the current work of leading researchers in this field were scanned.

Appendix 2

Results of literature review :

Studies investigating the experiences and needs of parents with a chronic illness or physical disability

Studies investigating impact of chronic illness or disability on parents

Condition	Year	Author	Mother or father ill?	Sample size	Method	Aim
Physical disability <i>205 different types. Most common-MS, RD, diabetes</i>	1992	Goodman	Mothers only	N=199	Questionnaire (closed questions)	Describe experiences before & after childbirth
Physical disability <i>MS, polio, accident, visual impairments & arthritis</i>	1996	The Association of Disabled Parents in Norfolk	24 mothers 13 fathers 5 both parents	N=42	Questionnaire (open & closed)	To reveal experiences common to disabled parents of school aged children
Physical disability <i>MS, RD, spina bifida, cerebral palsy, spinal cord injuries etc.</i>	1997	Wates	18 mothers 2 fathers 1 both parent	N=21	Individual interview (qualitative)	Describe parents' experiences
Range of disabilities <i>Physical, sensory impairments and/or learning difficulties</i>	2000	Goodinge	Mothers and fathers	N=621 But only 90 cases looked at in depth	Mixed methods: examination of social service records, questionnaire and individual interviews with parents	To evaluate the way councils with other agencies, managed and planned services for disabled adults to enhance their ability to parent
Range of disabilities <i>Physical, sensory impairments and/or learning difficulties</i>	2002	Wates	Not applicable	125 social service departments	Survey	To find out if social service departments in England have any policies or protocols in relation to providing services to parents with
Chronic illness <i>Breast cancer, diabetes, and fibrocystic breast disease</i>	1986	Stetz <i>et al.</i>	Mothers only	N=125	Individual interviews (qualitative)	To describes the type of coping strategies families use to manage problems of everyday living in their home when a mother has a chronic illness
Chronic illness <i>IBD, MS, RD, scleroderma</i>	1990	Thome	Mothers only	N=16	Individual interview (qualitative)	Describe parents' experiences
Chronic illness <i>non-metastatic breast cancer, fibrocystic breast changes, diabetes</i>	1995	Yates <i>et al.</i>	Mothers only	N=105	Standardised instruments	Assess impact of marital status & quality on family functioning
Chronic illness <i>diabetes, thyroid problems, MS, epilepsy, hyperemesis gravidarum, thrombosis, hypertension</i>	1999	Thomas	Mothers only	N=15	Individual interview (qualitative)	Describe experience of major illness during pregnancy
Chronic illness <i>systemic lupus, diabetes, hepatitis, end-stage renal failure, MS, etc.</i>	2002	Lundwall	15 mothers 2 fathers	N=17	Questionnaire (closed) posted on the internet	To describe perceptions of ability to parent and effect of condition on children
Cancer <i>type & severity unclear</i>	1985	Vess <i>et al.</i>	30 mothers 24 fathers	N=54	Standardised instruments	Assess reallocation of family roles
Cancer	1988	Vess <i>et al.</i>	30 mothers	N=54	Individual	Parents' views on

Studies Investigating Impact of chronic illness or disability on parents

Condition	Year	Author	Mother or father ill?	Sample size	Method	Aim
<i>type & severity unclear</i>			24 fathers		interview (qualitative)	sources of stress
Cancer <i>type & severity unclear</i>	1993	Hymovich	7 fathers 3 mothers	N=10	Individual interview (qualitative)	Parents' views on sources of stress & coping strategies
Cancer <i>type & severity unclear</i>	1998	Fitch <i>et al.</i>	Mothers only	N=47	Individual interview (qualitative)	Describe parents' experiences
Cancer <i>Type & severity unclear</i> <i>Undergoing treatment, 2months - 3yrs post diagnosis</i>	1999	Kayser <i>et al</i>	Mothers only	N=49	Standardised questionnaires	To examine the influence of relationship factors to examine the adjustment of women with young children to cancer.
Cancer <i>Type & severity unclear</i> <i>Undergoing treatment, 2months - 3yrs post diagnosis</i>	2002	Kayser & Somanti	Mothers only	N= 26	Individual interview (qualitative)	To examine how women being treated for cancer define themselves and rethink their identities in the context of a life-threatening illness.
Breast cancer <i>non-metastatic</i>	1986	Green	Mothers only	N=27	Family interview (qualitative & quantitative)	Assess reallocation of family roles
Breast cancer <i>early stages</i>	1992	Lewis & Hammond	Mothers only	N=111	Standardised instruments	Assess stability of maternal & family functioning
Breast cancer <i>early stages</i>	1996	Lewis <i>et al.</i>	Mothers only	N=123 <i>22 single 101 partnered</i>	Standardised instruments & individual interview (qualitative)	Describe experiences of single mothers & compare functioning with those who have partners
Breast cancer <i>early stages</i>	1996	Hilton	Mothers only	N=55 <i>Only 31% had child</i>	Family interview (qualitative)	To describe the process of normalization in families dealing with early stage breast cancer
Breast cancer <i>early stages</i>	1996	Hilton & Elfert	Mothers only	N=12	Family interview (qualitative)	Describe children's and parents' perceptions of the child's response to breast cancer
Breast cancer <i>early stages</i>	1998	Barnes	Mothers	N=3	Individual interview (qualitative)	To examine the impact of developmental problems in a child when a family is dealing with breast cancer in the mother
Breast cancer <i>early stages</i>	2000	Barnes	Mothers only	N=32	Individual interview (qualitative)	Describe parents' communication with children about illness
Arthritis	1987	Reisine <i>et al</i>	Mothers only	N=142	Questionnaire (closed questions)	Assess instrumental & nurturant role functioning
Rheumatic disease	1988	Allaire	Mothers only	N=25	Questionnaire (open & closed)	Describe parenting difficulties
Arthritis	1989	Geirdal	Mothers only	N=10	Group meetings	Describe parenting difficulties
Rheumatic diseases	1992	Ostensen & Rugelsjoen	Mothers only	N=57	Questionnaire (open & closed)	To investigate the practical problems experienced by the mother
Rheumatoid arthritis	1993	Le Gallez	13 mothers 9 fathers	N=22	Individual interview (qualitative)	Describe impact on family life
Arthritis	1999	Barlow <i>et al.</i>	Mothers Fathers	N=145	Questionnaire (open & closed)	To examine the realities of parenting

Studies Investigating Impact of chronic illness or disability on parents

Condition	Year	Author	Mother or father ill?	Sample size	Method	Aim
			Grandparents		& focus groups	from the perspective of mothers, fathers, and grandfathers with arthritis
Multiple sclerosis	1992	Crist <i>et al</i>	Mothers only	N=62 32 MS 32 control	Observation (quantitative)	Assess mother-daughter interaction
Multiple sclerosis	1994	Smeltzer <i>et al</i>	Mothers only	N=15	Individual interview (qualitative)	Describe concerns of pregnant women
Multiple sclerosis	1995	Blackford	Mothers and fathers	N=17	Individual interview (semi-structured)	To understand the experience of growing up with a parent who has MS
Multiple sclerosis	1998	Deatrick <i>et al</i>	Mothers only	N=35	Standardised instruments & Individual interview (qualitative)	Assess impact of symptoms on maternal physical affection
Multiple sclerosis	1998	Rehm & Cantanzaro	13 mothers 10 fathers	N=23	Individual interview (qualitative)	Describe parents' experiences & communication with child
Multiple sclerosis	2000	Steck <i>et al.</i>	Female participants were mothers	N=52 27 males 25 females	Standardised instruments	Coping with illness
Dialysis patients	1982	Friedlander & Viederman	Not stated	N=14	Interview (qualitative)	Parents' views on effects on child
Kidney disease	2001	Smith & Soliday	Mothers & fathers, breakdown not given	N=134	Questionnaire (open-ended)	Parents' views on effects on family
Insulin dependent diabetes	1985	Kornblum & Anderson	Mothers & fathers, breakdown not given	N=12	Interview (qualitative)	Parents' views on effects on family
Parkinson's disease	1992	Grimshaw	4 mothers 6 fathers	N=10	Individual interview (qualitative)	Describe parents' experiences
Asthma	1997	Cassino <i>et al</i>	Mothers only	N=48 24 asthma 24 control	Questionnaires (closed questions)	Compare performance of parenting duties & child's school attendance with control group
Narcolepsy	1995	Nehring & Cohen	Mothers only	N=40 20 narcolepsy 20 control	Standardised instruments	Identify parenting task difficult for mothers with chronic illness
Heart attack	1983	Dhooper	Unclear	N=40	Individual interview with spouse (semi-structured)	To understand the impact of heart attack on the family
Patient's hospitalised for critical care	1991	Titler <i>et al.</i>	Both 7 fathers 2 mothers	N=9	Individual interviews with patient, spouse, children, and nurses (qualitative)	To investigate perceptions of patients, spouses, children & nurses regarding the effects of adult hospitalization in a critical care setting
Spinal cord injury	1994	Westgern & Levi	Mothers only	N=29	Individual interview (qualitative)	To investigate views & experiences of patient, spouse & children regarding the perceived effects of maternal disability on various psychosocial functions & interactions in the family context.
Spinal cord	2000	Rintala <i>et al.</i>	Both	N=124	Standardised	To compare the

Studies Investigating Impact of chronic illness or disability on parents

Condition	Year	Author	Mother or father ill?	Sample size	Method	Aim
Injury				62 SCI 62 Control	instruments	parenting styles of parents with SCI with those without a disability, and the behaviour of their children aged 6-13 years.
Spinal cord Injury	2001	Alexander <i>et al.</i>	Mothers only	N= 172 88 SCI 84 control	Standardised instruments	To increase understanding about the division of family household tasks , family decision making, & the caring of children in families where mothers are disabled by SCI.
Spinal cord Injury	2002	Alexander <i>et al</i>	Mothers only	As above	As above	To examine the impact of SCI on mother's parenting, their marriage, their families and children's adjustment.

Appendix 3

Results of literature review: Quantitative studies on children's experiences

Quantitative studies of children's experiences

Year	Authors	Condition	Family Sample size	Mother or father ill?	Aim	Age of child	Data source
1981	Buck & Hohmann	Spinal cord injury	N= 81 SCI=45 Control=36	Father	To examine the relationships between parental disability & adjustment patterns in children.	18-30 yrs	Children (1 per family)
1982	Buck & Hohmann	Quadriplegia & paraplegia	N=16	Father	To assess adjustment patterns of children as a function of severity of disability in parents.	18-30 yrs	Children (1 per family)
1984	Lichtman et al	Breast cancer	N=78 34 % had children living at home	Mo	To document the changes that occur between patients & their children following breast cancer. Examine factors that influence these changes (severity of illness, treatment, patient's adjustment, & sex of child)	Not clear	Ill parent & partner
1985	Peters & Esses	MS Control	N=36 MS=33 Control=33	Both	To examine the functioning of families & ascertain whether the children perceive their family environment differently to children of non-MS parents	12-18 yrs	Children (1 per family)
1985	Hirsch et al.	Various	N=48 Depressed=13 RA=12 Control =11	Unclear	To understand the development of psychopathology.	12-18 yrs	Children 16 children per group
1985	Vess et al.	Cancer	N=54	Mothers and fathers	To assess reallocation of family roles	Under 20 years	Parent
1987 a	Hammen et al	Various	N= 58 Unipolar depression =13 Bipolar depression =9 Arthritis & diabetes =14 Healthy =22	Mother	To investigate the role of depressive symptoms & strain in the association between maternal affective disorder & child outcomes	8-16 yrs	Ill parent, children (1 per family) & teachers
1987 b	Hammen et al	As above		As above	To investigate the level, & psychosocial mechanisms of risk among children of mothers with affective disorders	As above	As above
1988	Klein et al	Various	N=61 unipolar depression =24 orthopedic & rheumatology patients=19 Healthy =18	Both	To explore the familial relationship between dysthymia in children (prolonged and disproportionate depression) & primary unipolar affective disorder in parent.	14-22 yrs	Children (1 per family)
1988	Moguilner et al	Hemodialysis patients	N=11	Both	To determine whether there is a relationship	8-17 yrs	Ill parent, partner &

Quantitative studies of children's experiences

Year	Authors	Condition	Family Sample size	Mother or father ill?	Aim	Age of child	Data source
					between parent's adjustment to chronic dialysis & their children's reaction		children
1988	Dura & Beck	Various	N=21 Pain =7 Diabetes=7 Healthy =7	Mother	To investigate the impact of maternal chronic pain on children	7-13 yrs	Ill parent, partner & children
1988	Rickard	Various	N= 63 Back pain=21 Diabetes= 21 Healthy= 21	Father	To investigate whether children of parents with chronic low back pain engage in more frequent sick-role behaviour.	9-12 yrs	Children & teachers
1989	Lewis <i>et al.</i>	Various	N=48 Breast cancer Diabetes Fibrocystic Breast cancer	Mother	Develop & test a model of family functioning.	School aged	Partner of ill parent
1989	Lee & Gotlib	Mixed sample	N= 71 Depressed =16 Non depressed patients = 10 Medical patients=8 Healthy = 27	Mother	To test whether child adjustment problems are specific to maternal depression & to stability of any observed effects.	7-13 yrs	Ill parent
1990	Mikail & von Baeyer	Chronic headache	N=54 Chronic headache = 24 Healthy=30	Unclear	(1) to compare the incidence of pain related illness & general behavioural disturbance among children whose parent's have chronic headache group with those whose parents are illness-free (2) to compare parent ratings of family functioning across groups.	9 and 17	Ill parent and children
1990	Stuifbergen	Various	N= 54 Cardiovascular disease=17 Arthritis =13 Diabetes=13 MS= 11	Both	To explore how the stress of chronic illness affects family functioning	Under 22 yrs	Ill parent and partner
1990	Hammen <i>et al</i>	Various	Unipolar depression =22 Bipolar depression =18 Diabetes & arthritis =14 Healthy =38	Mother	Longitudinal analysis of children's symptoms over the course of a parent's illness.	8-16 yrs	Ill parent and children
1991	Hammen <i>et al</i>	As above	As above	As above	1.Examine the temporal association of mothers	As above	As above

Quantitative studies of children's experiences

Year	Authors	Condition	Family Sample size	Mother or father ill?	Aim	Age of child	Data source
					and children's diagnosis during a longitudinal follow up of women with unipolar bipolar affective disorder, compared with medically ill and healthy women. 2 To examine the incidence of major depressive episodes over a period of up to 3 years in the children 3. To test whether stressors in children's lives precipitate symptomatology.		
1991	Wellisch <i>et al.</i>	Breast cancer	N= 120 Breast cancer=60 Healthy =60	Mother	To compare daughters of breast cancer patients with those whose mother is healthy on likelihood of being screened for breast cancer, feelings of conflict about screening procedures, psychological symptomatology, & body-image evaluations.	Adult children	Children
1992	Jamison & Walker	Chronic pain	N=42	Both	To investigate the level of somatic complaints in children of parents being treated at a pain centre.	6-18 yrs	Mother
1993	Chun <i>et al.</i>	Chronic pain	N=64 Chronic pain=35 Healthy=29	Both	To compare adjustment of children of chronic pain patients with that of healthy controls. Also to examine the relationship of specific parental factors to child adjustment	6-16 yrs	Both parents and teachers
1993	Conrad & Hammen	Various Unipolar Bipolar Medically ill Normal	N=69 Unipolar =22 Bipolar=18 Diabetes & arthritis = 24 Healthy =38	Mother	To investigate resource and protective factors (personal attributes, family factors and social support systems) in the development of psychopathology	8-16	Ill parent & children
1993	Adrian & Hammen	As above	As above	As above	To explore whether children of depressed mothers are exposed to unusually high levels of stress & experience elevated rates of stressful events to which they contribute?	As above	Ill parent & children
1993	Anderson & Hammen	As above	As above	As above	To examine the psychosocial functioning of children of depressed mothers & to assess the stability of children's psychosocial functioning over time.	As above	As above
1993	Lewis <i>et al.</i>	Breast cancer	N=40	Mother	To study the impact of mother's breast cancer on the household family	6-12 yr olds	Ill parent & partner
1994	Armsden & Lewis	Various	N= 48 Non	Mother	To describe children's psychological adjustment	6-12yrs	Ill parent & children

Quantitative studies of children's experiences

Year	Authors	Condition	Family Sample size	Mother or father ill?	Aim	Age of child	Data source
			metastatic breast cancer =13 Fibrocystic breast cancer =17 Diabetes=18		to their mother's breast cancer compared to normative data and compare with levels found in children of mother's with FBD or diabetes.		
1994	Le Clere & Kowalewski	Disabled	N=11,248	Both (includes step & foster parents)	To examine the effect of disability in any co-resident family member on the well-being of children with disabilities aged 5 – 17 years.	5-17 yr olds	Primary caregiver –80% mothers
1994	Compas <i>et al</i>	Cancer	N=117	Both	To investigate anxiety/depression and stress response symptoms in adult cancer patients, spouses and their children (aged 6-30 years).	6-30 yrs	Ill parent, spouse & children
1994	Howes <i>et al</i>	Breast cancer	N=32	Mo ther	To examine the relationship between medical & psychological factors in mothers with breast cancer & their children's psychosocial adjustment.	3-18 yrs	Ill parent
1995	Woods & Lewis	Mixed sample: breast cancer, diabetes FBC		Mother	To test a model of family functioning during a women's chronic illness	6-12 yrs	Ill parent
1995	Grant & Compas	Cancer	N=55	Both	To examine the mechanisms that mediate the relationship between maternal cancer& anxious-depressed symptoms in adolescent girls	11-18 yrs	Children (1 per family)
1996	Lewis & Hammond	Breast cancer	N= 70	Mother	To test a theoretical model of the impact of mother's breast cancer in adolescent-rearing households from mothers, fathers & adolescent's viewpoints.	Range unclear , mean = 16.3 years.	Ill parent, partner & children (1 per family)
1996	Lewis <i>et al</i>	Breast cancer – early stage	N=126 22 single 101 partnered	Mother	To describe the single woman's adjustment to & experience with breast cancer , compare her adjustment with that of married/partnered women , & describe the functioning of her children.	6yrs - adolescent	Ill parent & children (1 per family)
1996	Compas <i>et al</i>	Cancer	Numbers unclear	Both	To examine children, adolescents & young adults cognitive appraisals (seriousness, stressfulness & controllability of their parent's illness) & efforts at coping with their parent's illness	6-31 yrs	Children (N=134)

Quantitative studies of children's experiences

Year	Authors	Condition	Family Sample size	Mother or father ill?	Aim	Age of child	Data source
1996	Welch, Wadsworth & Compas	Cancer.	N=76	Both	To examine the psychological adjustment of children whose mothers or father recently received a diagnosis of cancer.	1-18 yrs	Ill parent or spouse & children aged 11-18 years (1 per family)
1996	Kotchick <i>et al.</i>	Hemophilia (HIV seropositive and negative)	N=75	Father	To examine the influence of coping by husbands, wives, & children in families where a father has haemophilia.	7-18 yrs	Ill parent, partner & children aged 7-18 yrs (1 per family)
1997	Cassinio <i>et al.</i>	Asthma	N= 48 24 asthma 24 control	Mother only	Compare performance of parenting duties & child's school attendance with control group	13 years or younger	Parent
1997	Forehand	As above	N=137	As in Kotchick <i>et al</i> (1996)	(1) Is there a relationship between level of hemophilia & psychosocial functioning of men, their wives & their child? (2) Does this relationship present after hemophilia is taken into account? (3) Is there any interaction between hemophilia & HIV status?	As in Kotchick <i>et al</i> (1996)	Ill parent, partner & children aged 7-18 yrs (1 per family)
1997 b	Steele <i>et al.</i>	As above	N=65	As in Kotchick <i>et al</i> (1996)	Examines whether parental uncertainty about the father's illness is positively related to child uncertainty. Also, whether children uncertainty is positively associated with internalising problems once the objective disease characteristics have been taken into account.	As in Kotchick <i>et al</i> (1996)	Ill parent, partner & children aged 7-18 yrs (1 per family)
1997 a	Kotchick <i>et al</i>	As above	N=53	As in Kotchick <i>et al</i> (1996)	To examine relationship between social support & psychosocial adjustment in children of men with hemophilia.	As in Kotchick <i>et al</i> (1996)	Ill parent, partner & children aged 7-18 yrs (1 per family)
1997 a	Steele <i>et al</i>	As above	N=69	As in Kotchick <i>et al</i> (1996)	To test a model of relationships among parental chronic illness, family process variables, avoidant coping strategies & childhood adjustment.	As in Kotchick <i>et al</i> (1996)	Ill parent, partner & children aged 7-18 yrs (1 per family)
1998	Brandt & Weinart	MS	N=174	Both	To determine which parent and family factors discriminated between youth at risk and not at risk of mental health problems in families where a parent has MS.	7-17yrs	Ill parent & spouse
1999	Birenbaum <i>et al</i>	Cancer	N=66	Both	To describe school aged children's adjustment to parental cancer and compare with normative	11-18yrs	Ill parent, partner & children (1 per family)

Quantitative studies of children's experiences

Year	Authors	Condition	Family Sample size	Mother or father ill?	Aim	Age of child	Data source
					population data.		
2001	Steck <i>et al.</i>	MS	N=52	Both	To investigate how parent's coping ability affects their children's capacity to cope, & how this is influenced by the gender of the children, patient and healthy parent.	3-23 yrs	Ill parent, partners, & children (1 per family)
2001	Hoke	Breast cancer	N=52 breast cancer =28 benign biopsy=24	Mother	(1) Are children of mother's with a recent diagnosis of breast cancer more poorly adjusted than control group? (2) Are medical characteristics of mother's illness related to children's adjustment? (3) Are the mother's psychological responses to illness related to children's adjustment?	8-18 yrs	Ill parent & children (1 per family)
2002	Nelson and While	Cancer	80	Both	To identify factors associated with poor and good adjustment in children.	8-16 years	Parents Teachers Children (1 per family)

Appendix 4

**Results of literature review :
Qualitative studies on children's experiences**

Qualitative studies on children's experiences							
Year	Condition	Authors	Sample size	Mother or father ill?	Aim	Age of children	Data source
1982	Dialysis patients	Friedlander & Viederman	20 families 20 children <i>dialysis=14</i> <i>control=6</i>	Not stated	To explore the impact of chronic dialysis of a parent on children living at home & on their relationship with the sick parent.	8-14 yrs	Ill parents & children
1983	Myocardial infarction	Dhooper	40 families Number of children unclear	Not stated	To understand the impact of a heart attack on the family & the coping strategies adopted.	62.5 % aged 8 month -19 yrs	Spouse of ill parent
1983	Mastectomy for breast cancer	Rosenfield <i>et al.</i>	8 children	Mother only	To investigate the needs of children when cancer is diagnosed in their parent, & the impact on psychological & social development.	Girls only 12-20yrs	Child
1985	Breast cancer	Lewis <i>et al</i>	126 families Number of children unclear	Mother only	To look at the implications of a mother having breast cancer for the family	7-19 years	Children
1988	Rheumatic disease	Allaire	26 families	Mother only	Describe parenting difficulties	Unclear	Mothers only
1990	Breast cancer	Issel <i>et al</i>	81 children	Mother only	To describe the ways in which children deal with their mother's breast cancer & how their family helps them cope.	6-20 years	Children
1990	Chronic illness <i>IBD, MS, RD, scleroderma</i>	Thorne	105 families	Mothers only	Describe parents' experiences	Age unclear, but still living at home	Mothers
1991	Spinal cord injury	Westgem & Levi	10 children	Mother only	To investigate views & experiences of patient, spouse & children regarding the perceived effects of maternal disability on various psychosocial functions & interactions in the family context.	10 yrs plus	Ill parent, spouse, and child
1991	MS	Blackford	17 families 29 children	Both	To describe what life is like when Mum or Dad has MS	8-19 yrs	Children & Ill parent
1991	Cancer Breast cancer Diabetes Fibrocystic breast disease	Hough <i>et al</i>	11 children	Mother only	To increase understanding of the adaption phase of chronic illness by comparing well & poorly adapted families in which a parent had a chronic illness.	No	Parents & observation of children
1991	Cancer	Stommel & Kingry	232 families 35 with children under 19 yrs	Not stated	To compare the support received by spouse-caregivers of cancer patients with minor children, with that of caregivers living alone or with adult children.	0-adult	Spouse of ill parent
1991	Critical care hospitalisation	Titler <i>et al</i>	10 families 11 children	Both	To describe perceptions of patients, spouses, children and nurses regarding the effects of parent hospitalisation in	5-18yrs	Ill parent, spouse, child, and teacher

Qualitative studies on children's experiences

Year	Condition	Authors	Sample size	Mother or father ill?	Aim	Age of children	Data source
					a critical care setting.		
1992	Parkinson's disease	Grimshaw	10 families 20 children	Both	To reflect the experiences of parents & children from families in which a parent has Parkinsons, to providing information that may be useful to other families	6-24 yr olds	Ill parent, spouse & children
1993	Critical care hospitalisation	Craft <i>et al.</i>	10 families 11 children	Both	To explore children's experiences when a parent is hospitalised for critical care.	7-18 yrs males only	Children
1993	Cancer	Hymovich	10 families	Both	Parent's views on sources of stress and coping strategies	0-20 years	Ill parent
1993	Rheumatoid arthritis	Le Gallez	22 families 40 children	Both	To assess the impact of RA on the marriage; sexual activity and satisfaction; the patient's work and partner's working pattern; the children.	11-30 yrs	All family members
1994	Cancer	Nelson <i>et al.</i> ,	16 families 24 children	Both	To identifying any problems & anxieties experienced by children related to their parent's illness, & investigate children's perceptions & understanding of the parent's cancer.	11 -21 yrs	Children
1995	MS	Blackford	17 families 29 children	Both	To understand the experience of growing up with a parent who has MS	8-19 yrs	Children
1995	MS	Cross & Rintell	21 children	Not stated	To examine children's perceptions of parental multiple sclerosis.	7-14 yrs	Children
1996	MS	Kalb	17 families 29 children	Not stated	To determine the effect of visible, physical symptoms in a parent, as well as less apparent psychological changes, on their children.	7-18 yrs	Ill parent & children
1996	Breast cancer-early stage	Hilton & Eifert	12	Mothers only	To describe children's responses to the cancer situation.	2-21 yrs	Whole family, including children aged 6-21 years
1996	Physical disability <i>MS, polio, sccident, visual impairment, arthritis</i>	National Association of Disabled Parents in Norfolk	42 families	Mothers and fathers	To reveal experiences common to disabled parents of school aged children	School - aged	Parent
1997	Physical disability <i>MS, RD, spina bifida, cerebral palsy, spinal cord injuries etc.</i>	Wates	21 families	Mothers and fathers	To describe parent's experiences	??????	Parent
1998	Breast cancer-stages 0-11	Zahlis & Lewis	26 families 36 children	Mother only	Describe times during their diagnosis & treatment that were most difficult for their children; behaviours observed that signalled	8-12 yrs	Ill parent

Qualitative studies on children's experiences

Year	Condition	Authors	Sample size	Mother or father ill?	Aim	Age of children	Data source
					the child was having a difficult time; and what prevented mother from helping child at this time		
1998	MS	Rehm & Cantazaro	23 families	Both	To examine family members' perceptions of the effects of chronic illness on parenting when one parent has MS	7-16 yrs	Ill parent, spouse & children 11-16 years
1999	Arthritis	Barlow <i>et al.</i>	145 families	Mothers, fathers & grandparents	To examine the realities of parenting from the perspective of mothers, fathers, and grandfathers with arthritis	0-15 years	Ill Parent or grandparent
2000	Cancer – early stage or remission	Chalmers	27 families 33 children	Both	To elicit adolescent's description of their information and support needs in response to their mother's breast cancer	12-20 yrs	Child
2001	Breast cancer	Hooper Zahlis	11 families 16 children	Mother	To understand concerns & sources of distress children experience when their mother is diagnosed with early stage breast cancer	11-18 yrs	Child
2001	Kidney disease	Smith and Soliday	134 families	Mothers & fathers, breakdown not given	Parents' views on effects on family	Under 18 years	Parent
2002	Chronic illness	Lundwall	17 families	Both	To describe perceptions of ability to parent and effect of condition on children	6-35 yrs	Parent

Appendix 5

Study 1:
Letter from consultant in Site B

Dear

You will be receiving with this letter some details of a project of the University of York which is trying to help our understanding of the impact of inflammatory bowel disease (Crohn's or ulcerative colitis) on parents and their children. This study does not involve you in any tests or treatment alterations as you can see from the enclosed information.

The project is being financed by NACC and may prove a valuable contribution to our knowledge. The Combined Gastroenterology Service in [REDACTED] are happy to endorse this project and hope very much that you will be able to find the time to take part.

Yours sincerely

Appendix 6

**Study 1:
Information leaflet for parents**

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

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

ORIGINS OF THE RESEARCH

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

AIM OF THE RESEARCH

The aim of the research is to investigate:

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

WHY IS THE RESEARCH IMPORTANT?

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

WHO IS CARRYING OUT THE RESEARCH

Two researchers from the Social Policy Research Unit (SPRU), University of York, are carrying out the study. Our names are Tricia Sloper and Suzanne Mukherjee. We have both worked in research for many years and have a lot of experience in carrying out similar research. SPRU has a long established and successful record of social science research on disability and chronic illness and family life, as well as expertise in consulting children, parents and professionals. If you are interested to know more about us and have access to the internet, you might like to take a look at our web site: <http://www.york.ac.uk/inst/spru/>

WHO SHOULD TAKE PART?

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

experiences.

WHAT DOES TAKING PART INVOLVE?

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

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

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

WHAT WILL HAPPEN TO THE INFORMATION YOU PROVIDE?

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

THE TIMETABLE

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

WHAT HAPPENS NEXT

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

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

Appendix 7

**Study 1:
Focus group topic guide**

FOCUS GROUP TOPIC GUIDE

PRELIMINARIES

Consent form

Expenses

Short questionnaire on health and family circumstances

WELCOME AND INTRODUCTIONS

(Researcher 1)

Thanks for coming to the meeting

Introduce the researchers

Explain the purpose of the research study

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

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

The plan for meeting

During the meeting, we will talk about :

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

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

Tape recording

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

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

Ground rules

When we run meetings like this we usually find it quite useful to have a few ground rules. These are (refer to poster on wall) :

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

Does anyone want to add anything to this, change anything?

House keeping

Please feel free to help your self to drinks.
Also to go in and out of the meeting as you wish.

Introductions

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

GENERAL QUESTIONS ABOUT IBD

(Researcher 1)

What we would like to do now is begin the discussion by asking you to think generally about the effects of your condition on everyday life. To help you do this, we are going to give you a

couple of minutes to think about this on your own. Can you take a slip of paper and write down the three main ways in which IBD affects your everyday life. Once you have done, this we will come back together and have a short discussion about it.

HOW IBD AFFECTS YOU AS A PARENT

(Researcher 2)

Now moving on to focus in on one aspects of people's lives - being a parent. We would like you to think about both the positive and negative ways in which IBD has affected you as a parent. To help you do this, we would like you to think use this time line (see appendix 10). Ignore the bottom half of the page for now, and write on the top half how IBD has affected you as a parent during the different phases of your child's life: when you child was of pre school age, primary school age, and secondary school. Those of you with younger children will only be able to complete part of the time line. We would like you to use a red pen to write about positive effects and black pen for negative effects. We will leave you for about 10 minutes to work on your time line and then we will come back together as a group to discuss it.

THE EFFECTS YOU HAVE NOTICED IN YOUR CHILDREN

(Researcher 2)

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

WAYS OF DEALING WITH DIFFICULTIES

(Researcher 1)

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

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

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

TALKING TO CHILDREN

(Researcher 1)

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

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

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

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

THE SUPPORT PARENTS WITH IBD WOULD LIKE FROM SERVICES
(Researcher 2)

Have you any messages for people providing services.

- I. about support for parents
- II. about support for children

By services we mean health, education, social services or the voluntary sector.

CLOSURE
(Researcher 1)

Thank you

What happens next

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

Appendix 8

**Study 1:
Consent form**

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

CONSENT FORM

Please tick the boxes below as appropriate

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

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

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

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

Signature:

Date:

Appendix 9

Study 1:
Questionnaire on family circumstances and health

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

BACKGROUND INFORMATION

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

Name

Date of birth

Please tick the boxes below as appropriate.

How did you first find out about the project ?

Through meeting a researcher in the hospital

Through receiving a letter from you consultant

Through the local NACC group

Other (please specify)

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

Yes

No

FAMILY CIRCUMSTANCES

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

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

Do you live with a partner/spouse?

No

Yes

Are you working at present ?

No

Yes, part-time

Yes, full-time

If yes, please state occupation

ILLNESS EXPERIENCE

How long have you had symptoms of inflammatory bowel disease?

How long is it since you were first diagnosed?

Please state your diagnosis

Ulcerative colitis

Crohn's disease

Other (please specify)

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

Yes

No

If yes, please describe:

.....
.....
.....
.....
.....
.....
.....

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

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

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

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

Thank you very much for completing this questionnaire.

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

Appendix 10

Study 1: Time line

THE TIME LINE

How IBD has affected you as a parent

.....PRESCHOOL..... PRIMARY SCHOOL..... SECONDARY SCHOOL.....

0-4 years

5-10 years

11-16 years

The effects you have noticed in your children

Appendix 11

Study 2:

Letter and response form for young advisors

Dear XXXXXX

I am a student at York University. I am going to be carrying out a project with some children who have a parent who is ill a lot of the time. I want to find out what life is like for them. I know your Mum is *not* ill, but I wondered if you would be an advisor to the project?

I could do with some help in making sure the questions I ask people make sense. I am also trying to make the project as much fun to take part in as I can. These are the sorts of things I am hoping you can give me advice on.

When we meet, I plan to tell you about the questions I am thinking of asking the children who take part in the project. Then you can tell me what you think of them. Please tell me the truth, even if you think they're rubbish! Maybe we can test a few questions out? If you don't mind, I will tape record our meeting, just so I don't forget the things we talk about.

If you want to ask me any questions about being an advisor, you can call me at home in the evening. My telephone number is XXXXXXXX.

If you want to take part, please could you fill in the form with this letter or give me a ring at home. Then we can arrange to meet.

Thanks
Suzanne

RESPONSE FORM

INVITATION TO BE A PROJECT ADVISOR

NAME.....

Please tick the box below

I would like to be an advisor to the project

Please write below the times when you could meet me:

Appendix 12

Study 2 :
Parent information leaflet and response form

Information for parents

The project on 'When Mum or Dad feels ill'

February 2001

In the summer of 2000, two researchers from the Social Policy Research Unit – Suzanne Mukherjee and Tricia Sloper- carried out a research study on the impact of inflammatory bowel disease (IBD) on parents and their children. The research revealed a number of areas where parents felt support for families could be improved. However, the study did not gather the views of children and young people in the family. Many parents who took part in the first study felt it was important that their children be consulted. Suzanne Mukherjee is now carrying out a new project involving children. This leaflet provides you with some information on the new project so that you can decide whether or not you are happy for your children to take part in the project.

The purpose of the study

The purpose of this research project is to find out about the views and experiences of children whose parent has IBD. What do children know and understand about their parent's IBD? What difference does it make to their everyday life? What strategies do they use to deal with any difficulties they experience? Is there anything they would like help with?

Who is carrying out the research?

Suzanne Mukherjee, one of the researchers involved in the previous research project with parents, is carrying out the research. Suzanne is an experienced researcher who has worked on a number of projects involving children. At present, Suzanne is a student in the Department of Health Studies, University of York, and is completing this project as part of her work towards a PhD.

How will my family benefit from this study?

Your family will not benefit directly from the study. The aim of the study is to provide information for two groups of people:

- Families in which a parent has IBD, who want advice on what to expect and ideas on how to manage.
- Professionals and managers within health, social services, education, and the voluntary sector, who are in a position to improve services for patients with IBD and their families.

Who is taking part in the project?

All the families who took part in the first research study who have a child aged seven years or older are invited to take part. Many families will have more than one child in this age range. To make sure I find about children's different views and experiences, I am hoping to speak to all the children in each family and would like to meet with each child individually.

What is involved?

If your child is interested in taking part in the project, I will visit them at a time and place that is convenient to them. This can be in your home, or anywhere else that they choose

and is convenient to you. Before I meet with your child, I will contact you to have a short discussion about what they understand about your health.

Before I begin talking with your child, I will spend some time explaining to them that everything discussed is confidential, they can skip any questions they do not want to answer, and that we can stop the interview at any time they want. They will be asked to sign a form stating that they consent to taking part and they will be given a copy of this form to keep. I will begin with a general chat about school, hobbies etc. Then we will go on to discuss what happens when you are unwell, how they feel about it, and whether they have any advice for other children about things that help. Younger children may prefer to tell me about their experiences by doing something more practical, like a drawing or making a collage. The length of time the interview takes will vary depending on how much your child has to say. For younger children, it may take as little as twenty minutes.

What will happen with the information?

I will do three things with the information from the project:

1. I will write a booklet about what it is like for children and young people when a Mum or Dad is ill. *All children who take part in the project will get a copy of the booklet.*
2. I will write an article on the findings for a journal read by professionals who support people with IBD and their families.
3. I will include the research findings in a longer report, which I will submit to the University of York for my PhD.

Will anyone else be told what my child says?

No, everything we discuss is confidential. Their name will not be used when I write up a report of the project. It also means I cannot discuss what they say with their parents, brothers and sisters, or anyone else, without their permission.

Does my child have to take part ?

No, participation in the project is completely voluntary. Whether or not your child takes part in the research will have no influence on the care and support you receive from health services or anyone else.

What happens next?

I would be grateful if you would pass on the enclosed information leaflets to your children.

If they are definitely *not* interested in taking part...

That's fine, I understand.

If you think they *might* be interested in taking part...

Please make sure they send back the response slip, enclosing your phone number. I will then contact them to discuss the project and answer any questions they might have. Sending back the form does not commit them to taking part. I will only telephone to talk about the project. If they then decide they want to take part, I will arrange a time to meet.

Whether or not they want to take part, please ask your children to send back the response form so that I know what they have decided!

If you would like any further information, please contact Suzanne Mukherjee,
Department of Health Studies, Genesis 6, Science Park, University Road, York, YO10 5DQ
Telephone 01904 433118

PARENT'S RESPONSE FORM

The project on 'When Mum or Dad feels ill'

NAME.....

ADDRESS.....
.....
.....
.....

TELEPHONE NUMBER.....

Please tick one of the following:

- I am happy for my children to take part in the project and have passed on the project information packs.*

- I do not want my children to take part in the project*

If you have decided you do not want your children to take part, I would be very grateful if you could tell me your reasons. You can do this by writing in the space below.

.....
.....
.....
.....
.....

Please return this form in the envelope provided to: Suzanne Mukherjee,
Department of Health Studies, Genesis 6, Science Park, University of York,
YO10 5DQ Or telephone me on 01904 434118

Appendix 13

**Study 2 :Child's invitation and response form
(6-10 years)**

Invitation

The project on 'When Mum or Dad feels ill'

February 2001

Hello.....

My name is Suzanne and I am a student at the University of York. Last year I carried out a project where I spoke to your [Mum/Dad] about what it is like when [s/he] has an upset tummy and has to go to the toilet a lot. This year I would like to invite you to take part in the project.

I would like to know more about what life is like for you when your [Mum/Dad] is not well. This is important because adults don't always know what life is like for young people.

I am writing to 30 children asking them to take part. Some people will be from the same family. I would like to speak to all the brothers and sisters in a family to get their views. To make sure I find out about your different views, I would like to meet with brothers and sisters separately.

If you want to take part, we can meet wherever you want. Maybe at home? It's up to you.

What you tell me will be kept private.

At the end of the project, I will write a booklet about what it is like for children and young people when a Mum or Dad is not

feeling well. You will get a copy of the booklet. The project will also help people like doctors, nurses, and teachers know more about how they can help families.

If you decide you might like to take part in the project, fill in the white form saying 'yes' and send it back to me in envelope attached to it. Then I will telephone you and, if you want, we can arrange to meet.

It is up to you whether you take part in the project. If you don't want to take part, that's OK. Just say no! Even if you say yes, you can change your mind later. That's OK.

Thank you for reading this letter.

Suzanne

YOUNG PERSON'S RESPONSE FORM

The project on 'When Mum or Dad feels ill'

NAME.....AGE.....

ADDRESS.....

.....

.....

.....

.....

Please tick one of the following:

(03)

I am interested in taking part in the project

If you are interested in taking part, please tell me your telephone number so I can contact you to tell you more about the project.

Your telephone number is ☎.....

The best time for me to telephone you is ⌚.....

(03)

I do not want to take part in the project

Please return this form in the envelope provided to:
Suzanne Mukherjee, Department of Health Studies, Genesis 6, Science
Park, University of York, YO10 5DQ
Or telephone me on 01904 434118



Thanks

Appendix 14

Study 2 : Child's information leaflet and response form (10-16 years)

INVITATION

The project on 'When Mum or Dad feels ill'

March 2001

Hello

My name is Suzanne and I am a student at the University of York. I have carried out lots of projects with children and young people to find out their views on things. This leaflet is to invite you to take part in a new project called 'When Mum or Dad feels ill'.

Why am I writing to you?

Last year I carried out a project where I spoke to parents about what family life is like when they are unwell - when they have an upset stomach and have to go to the toilet a lot. I found out lots of things, but I did not get to hear about what life is like for children and young people in the family. This year I am inviting children and young people to take part in the project.

How did you get my name and address?

If you get a leaflet from me, that's because your Mum or Dad has already taken part in the project and gave me permission to write to you.

What are you trying to find out from me?

Last year I spoke with parents about what it's like for them when they're not feeling well and how they manage. Now I'd like to find out:

- What is it like for you when your Mum is not well?
- Have you got any advice for other young people whose Mum or Dad has recently become ill?

Even if you feel that your Mum being ill has made no difference to you or your family, I am interested in meeting you. It is important for me to know that this is what you think!

What is the point of the project?

The information from the project can help in two ways:

- It can help other young people to know what to expect if their parent becomes ill, and give them ideas on how to manage.
- It can help people like doctors, nurses, and teachers provide better support for families.

Who is taking part in the project?

I am inviting 30 children and young people to take part. Some people will be from the same family. I would like to speak all the brothers and sisters in a family. After all,

brothers and sisters can have different views on things! To make sure I find out about your different views, I would like to meet with brothers and sisters separately.

What will I have to do?

First, I will telephone to talk to you about the project. You can then decide whether you want to take part.

If you want to take part, we can arrange to meet. Whenever we meet, it will be at a time and place that suits you. We can meet in your home, or somewhere else if you prefer. I will ask you to sign a form saying that you are happy to take part in the project. You will be given a copy of this form to keep. We will then have a chat about your experiences and any advice you would like to pass on to other young people

What will happen with the information?

I will do two things with the information from the project:

1. I will write reports and articles on the project.
2. I will write a booklet about what it is like for children and young people when a Mum or Dad is ill. You will get a copy of the booklet.

Will anyone else be told what I say?

No, everything we discuss is confidential. This means I will not discuss it with your parents, sisters or brothers, or anyone else without your permission. Your name will not be used when I write up the project report or booklet.

Do I have to take part in the project?

No, you do not have to take part in the project. If you decide not to take part, I will accept your decision and I will not ask you to give a reason.

What happens next?

If you decide you might like to take part in the project, fill in the form attached to this letter saying 'yes'. This just means you *might* like to take part, but you can still change your mind at any time. I will then phone you, we can talk about the project, and if you want we can arrange to meet.

Whether or not you want to take part, please send back the response form so that I know what you have decided! Thank you for reading this letter.

Suzanne

If you would like to talk to me about the project, telephone 01904 434118 between 9.00am and 5.30 pm Monday to Friday. If I am not there, please leave a message on the answer phone.

YOUNG PERSON'S RESPONSE FORM

The project on 'When Mum or Dad feels ill'

NAME.....AGE.....

ADDRESS.....
.....
.....
.....

Please tick one of the following:

(03)

I am interested in taking part in the project

If you are interested in taking part, please tell me your telephone number so I can contact you to tell you more about the project.

Your telephone number is ☎.....

The best time for me to telephone you is ⌚

(03)

I do not want to take part in the project

Please return this form in the envelope provided to:
Suzanne Mukherjee, Department of Health Studies, Genesis 6, Science
Park, University of York, YO10 5DQ
Or telephone me on 01904 434118



Appendix 15

**Study 2 :
Child's information leaflet and response form
(16 years plus)**

INVITATION

The project on 'When Mum or Dad feels ill'

March 2001

In the summer of 2000, two researchers from the University of York - Suzanne Mukherjee and Tricia Sloper- carried out a research project on 'Understanding the impact of inflammatory bowel disease (ulcerative colitis or Crohn's) on parents and their children'. The research revealed a number of ways in which parents felt support for families could be improved. However, the study did not gather the views of children and young people in the family. Suzanne Mukherjee is now carrying out a project to find out about the views and experiences of children whose parent has IBD. The purpose of this leaflet is to tell you what this research involves and invite you to take part.

Who is carrying out the research?

Suzanne Mukherjee, one of the researchers involved in the previous project with parents, is carrying out the research. At present, Suzanne is a student in the Department of Health Studies, University of York, and is completing this project as part of her work towards a PhD.

Who is taking part in the project?

All the families who took part in the first research study, who have a child aged seven years or older, are invited to take part. Many families will have more than one child in this age range. I am hoping to speak to all the children in each family. To make sure I find out about the different views of people in the same family, I would like to meet with brothers and sisters separately.

What would you like to talk to me about?

I would like to talk with you about :

- What difference your parent having IBD made to everyday life when you were growing up - both the positive and the negative aspects.
- How you dealt with any difficulties you experienced
- Any advice you would like to pass on to other children or young people who have recently found out one of their parents has IBD
- Any views you have on the type of help that would be useful to families

Even if you feel that your Mum or Dad being ill has made no difference to you or your family, I am interested in meeting you. It is important for me to hear about positive experiences, as well as any difficulties.

What is involved?

If you are interested in taking part in the project, I will arrange to interview you at a time and place that is convenient to you. This can be in your home, or anywhere else that suits you.

I will ask you to sign a form saying that you're happy to take part and you will be given a copy of this form to keep. We will have a discussion about your experiences and any advice you would like to pass on to other young people, parents or professionals. The length of time the interview takes will vary depending on how much you have to say. It is probably best to set an hour and a half aside for the interview.

How will my family benefit from this study?

Your family will not benefit directly from the study. The aim of the study is to provide information for two groups of people:

- Families in which a parent has IBD, who want advice on what to expect and ideas on how to manage.
- Professionals and managers within health, social services, education, and the voluntary sector, who are in a position to improve services for patients with IBD and their families.

What will happen with the information?

The information from the project will be used to:

1. Write a booklet about what it is like for children and young people when a Mum or Dad is ill. Everyone who takes part in the project will get a copy of the booklet.
2. Write reports and articles on the support needed by families in which a parent has IBD.

Will anyone else be told what I say?

No, everything we discuss is confidential. Your name will not be used when I write the project report or booklet. I will also not discuss what you say with your parents, brothers and sisters, or anyone else, without your permission.

What happens next?

If you are definitely *not* interested in taking part...

That's fine, I understand.

If you think you *might* be interested in taking part...

Please make sure you send back the response slip attached to this letter, enclosing your phone number. I will then contact you to discuss the project and answer any questions you might have. Sending back the form does *not* commit you to taking part. I will only telephone to talk about the project. If you then decide you want to take part, we will arrange a time to meet.

Whether or not you want to take part, please send back the response form so that I know what you have decided! Thank you for reading this leaflet.

Suzanne Mukherjee

If you would like to talk to me about the project, telephone 01904 434118 between 9.00am and 5.30 pm Monday to Friday. If I am not there, please leave a message on the answer phone.

YOUNG PERSON'S RESPONSE FORM

The project on 'When Mum or Dad feels ill'

NAME.....AGE.....

ADDRESS.....
.....
.....
.....

Please tick one of the following:

(03)

I am interested in taking part in the project

If you are interested in taking part, please tell me your telephone number so I can contact you to tell you more about the project.

Your telephone number is ☎.....

The best time for me to telephone you is 🕒.....

(03)

I do not want to take part in the project

Please return this form in the envelope provided to:
Suzanne Mukherjee, Department of Health Studies, Genesis 6, Science
Park, University of York, YO10 5DQ
Or telephone me on 01904 434118



Thanks

Appendix 16

**Study 2:
Interview topic guide for 7-16 year olds**

INTERVIEW TOPIC GUIDE

Research project on 'When Mum or Dad feels ill'

Young people aged 7- 16 years

Materials: Tape recorder, Tapes, Batteries, List of codes, Contract form, Parent's Consent forms, Child's consent form, SIBDQ questionnaire, Sheet of topics, Headed paper, Timeline, Figure of person, 'How often' sheet, 'A message' sheet, 'Feeling faces' sheet, 'What happens next' form, Box for 'messages', Colouring pens.

INTRODUCTIONS

I am a researcher at the University in York. At the moment, I am doing a project on what it is like in families when a Mum or Dad is not well. I have spoken to your Mum/ Dad and they have told me that sometimes they are not well. They said you know that(seek advice from parents on appropriate wording e.g. they sometimes have a sore tummy/ they have something called Crohn's etc). Is that right?

I talked with your Mum/Dad about what it is like for them to have.....and about some of the things that happen when they aren't feeling well. I have also spoken to lot of other Mums and Dads about the same thing. Now I would like to find out what it is like for children when their Mum or Dad isn't well. That's why I have come along to see you today.

Whose idea was it that you talked to me today?

>>was it yours or your Mum/Dad's

What made you decide to talk to me?

I am going to be speaking to lots of other boys/girls/teenagers who live in and around XXXXXX who have a Mum or Dad who has over the next few weeks.

One of the reasons for wanting to know about all this is that it might help other families who have just found out that their Mum or Dad has.....if they know what to expect.

I am also hoping that people will be able to tell me about some of the things they do, or other people do, that help when their Mum/Dad is not well.

When I have finished talking with all the other people I am meeting over the next few weeks, I will put all the information and write a short book for children/teenagers to read. You will get a copy of the book.

CONSENT AND CONFIDENTIALITY

What I would like to do today is find out a little about you and talk with you about what happens when your Mum/Dad isn't feeling very well.

Everything we talk about today is private. That means that I will not tell anyone else what we talk about – not you Mum, or Dad, your brothers and sisters, or anyone else.

The only time I will break that promise is if you tell me something that makes me worried that someone is doing something to hurt you in some way.

What you tell me today will be included in the book, but I won't use your name so it will be kept private (check that you know what this means). Is that alright? I will send you a copy of this book when it is finished.

There might be questions that you don't know the answer to. That's OK. All you have to do is tell me.

Sometimes when we're talking there may be things I ask you which don't make a lot of sense because of the way I have asked the question. If that happens you can tell me you don't understand and I will ask you a different question.

There may be things I ask which you don't want to answer. That's OK too. All you have to do is tell me you want to pass (red card system for primary aged children). Then I'll go on to the next question.

As I said before, what I'd like to do today is find out a little bit about you and what it's like in your family when your Mum/Dad isn't well. To help us, I had a think before I came to see you

about some of the things that we could talk about. Maybe we would start with them and then if we have missed anything that's important we can add them. The things I thought of are:

>>prompt sheet

(A bit about you, Your family, Your Mum /Dad and what happens when s/he is not well, Things that help when Mum/ Dad is not well, Messages for other children)

I would like to use this tape-recorder when we are talking to help me remember what you say. To make sure the tape is kept private. I won't use your names on it. I will use a code number instead. After I go away today, I will listen to and write down what we have talked about, but no else gets to listen to it. Is that OK? If you prefer, I can just write a few things down while we talk if you want.

When I have made notes from the tape, I wipe them clean so there is nothing recorded on them. That way, no one else gets to hear what is on the tape. If you prefer, you can have the tape to keep.

You don't have to talk to me, it's up to you. What do you think?

Ask child to sign consent form

Sign promise of confidentiality form

Set up tape recorder with child, giving them some codes to choose from

INTRODUCTION TO INTERVIEW

I have brought lots of things with me to help us talk about these things – coloured paper, pens, stickers. Then while we are talking, you can always do some draw some diagrams or some pictures. If you decide to do some drawings, we could use them to decorate the book I will write at the end of the project. You don't have to do things like that if you don't want. If you prefer, we can just talk.

At the end of the interview, we will put the tape and everything else together in a box. The box is all about you and your family. Everyone who takes part in the project will have their own box. At the end of the project, all the information from all the boxes will be used to write the book.

A BIT ABOUT YOU

I thought it would be good to begin with some stuff about you.

- **First, can you tell me what age you are ?**

Do you want to write that on the page?

- **Where do you go to school?**

> **Is it near to here or far away?**

- **How do you get to/get back from school?**

➤ **Do you walk or get the bus or go in a car?**

➤ **Does anyone go with you? Your Mum, Dad, brothers or sisters?**

Draw a picture of you going to school

- **What do you like/ not like doing in school?**

Write a list of things I like/don't like about school

- **What things do you like doing at weekends/on holidays?**

Sentence completion :

'At weekends I like to.....'

'During school holidays I like to.....'

- **If you were writing a letter to someone you had not met before, is there anything else you would want to tell them about yourself?**

If has not put anything on the page:

We've talked about lots of different things about you, do you want to draw or write about any of them on this page?

YOUR FAMILY

Who lives in your house?

- Do you have any brothers and sisters? What age are they?
- Do you have any pets?

Draw map of house/ family members

Is there anyone else in your family who does not live in your house at the moment?

- *Brothers and sisters ?*

What things do your family like doing at weekends/holidays/in the evening?

Draw things you like to do/write a list

If you were telling someone else who hadn't met your family before what they were like, is there anything else you would want to tell them?

YOUR MUM/DAD

Next I thought we might talk a little about your Mum/Dad. First, I'd like to find out what your Mum/Dad is like generally.

General

If you were describing your Mum/Dad to a friend who had not met her/him before, what would you tell them?

*****Use figure*****

- You might want to say something about what she's like
- What does she look like?
- What does she like doing?

Beliefs About Parent's Health

Now I'd like to talk about your Mum/Dad not being very well.

Do you remember what age you were when you first noticed that your Mum/Dad wasn't well?

- *Do you remember what else was happening?*
- *Do you remember what school you were at?*

******Use timeline******

Why did you think s/he wasn't well?

- Can you describe it using the diagram?

*******Colour in figure*******

How did you find out?

How did you feel about it?

Now that you're a bit older and know a bit more, what would you tell other children/young people about why your Mum/ Dad's is poorly sometimes?

Do you think it's serious or not?

What Happens When Mum/Dad Is Not Well

What sorts of things happen when your Mum/Dad is not well?

If it's a *school day* and you wake up and your Mum/Dad isn't well, what happens next?

Suggest can do a drawing/make a list/ use a matrix.

- >What does your Mum/Dad do?
- >What do you do?
- >What do your brothers and sisters do?
- >What does other parent do?

If it is a *weekend* and you wake up and your Mum/Dad isn't well, what happens next?

- >What does your Mum/Dad do?
- >What do you do?
- >What do your brothers and sisters do
- >What does other parent do?

If it's a *school holiday* and your Mum/Dad isn't well, what happens next?

- >What does your Mum/Dad do?
- >What do you do?
- >What do your brothers and sisters do
- >What does other parent do?

Is there *anything else* that happens when your Mum/dad is not well?

- > Does anything happen that doesn't usually happen?

How do you feel when these things happen?

Add word bubbles, Only use feeling faces if stuck

Which of the feelings you have told me about do you show/not show people?

IF NEG EMOTION, 'what do you do to make yourself feel better?'

IF UNSURE, 'can you think of anything that might make you feel better?'

Retrospective Data

What was it like when you were younger and your Mum/Dad wasn't well?

➤ Was it the same as it is now, or different?

Use time line while talking

How did you feel then?

Add feelings to timeline.

How Often

At the moment, how often is your Mum/Dad poorly?

> never or all the time

Use scale

Meeting Other People

Have you ever met anyone else who had a Mum or Dad who was sometimes not very well like your Mum/Dad?

If yes,

What was that like? How did you feel?

If no,

Would like to? Why?

THINGS THAT HELP

First, I would like to talk about things you do. Then we'll talk about things other people do.

Things You Do

Is there anything you do that helps *you feel* better when your Mum/dad is not well?

Is there anything you do *to help other people* in your family when your Mum /Dad is not well?

Things Other People Do

Draw diagram of people that help.

Does anyone else do anything that *helps you* when Mum/Dad is not well?

Does anyone else do anything to *help other people in your family* when Mum/Dad is not well?

Is There Anything Your Mum Does That Helps Her?

To feel better?

In some other way?

HELP WANTED

Is there any other help you would like for you or your Mum/dad or anyone else in your family?

Alternative for younger children

If you had a magic wand and you could make any help you wanted appear, what would it be?

MESSAGES FOR OTHER CHILDREN

If you could put a message in the box to send to their children, what would it be?

Use message sheet.

Is there anything else to add to the box?

Go through box together

CLOSURE

- **Thanks**
- **Remind will send them a summary/book about the project**
- **Use form:**
 - Ask them to nominate an alternative name
 - Check what they want returned
- **Discuss what they are doing for the rest of the day**

Appendix 17

**Study 2:
Interview topic guide for 16 years plus**

INTERVIEW TOPIC GUIDE

Research project on 'When Mum or Dad feels ill'

Young people aged 16 plus

Materials: *Tape, batteries, parent's IBDQ, consent form, timeline, scale, message sheet, 'what happens next form', spare paper*

INTRODUCTIONS

I am a researcher at the University in York. At the moment, I am doing a project on what it is like in families when a Mum or Dad is not well. I have spoken to your Mum/ Dad and they have told me that sometimes they are not well. They said you know that(seek advice from parents on appropriate wording e.g. they sometimes have a sore tummy/ they have something called Crohn's etc). Is that right?

I talked with your Mum/Dad about what it is like for them to have.....and about some of the things that happen when they aren't feeling well. I have also spoken to lot of other Mums and Dads about the same thing. Now I would like to find out what it is like for children when their Mum or Dad isn't well. That's why I have come along to see you today.

What made you decide to talk to me?

I am going to be speaking to lots of other boys/girls/teenagers who live in and around XXXXXX who have a Mum or Dad who has over the next few weeks.

One of the reasons for wanting to know about all this is that it might help other families who have just found out that their Mum or Dad has.....if they know what to expect. I am also hoping that people will be able to tell me about some of the things they do, or other people do, that help when their Mum/Dad is not well.

When I have finished to talking with all the other people I am meeting over the next few weeks, I will put all the information and write a short book for children/teenagers to read. You will get a copy of the book.

CONSENT AND CONFIDENTIALITY

What I would like to do today is find out a little about you and talk with you about what happens when your Mum/Dad isn't feeling very well.

Everything we talk about today is private. That means that I will not tell anyone else what we talk about – not you Mum, or Dad, your brothers and sisters, or anyone else.

The only time I will break that promise is if you tell me something that makes me worried that someone is doing something to hurt you in some way.

What you tell me today will be included in the book, but I won't use your name so it will be kept private (check that know what this means). Is that all right? I will send you a copy of this book when it is finished.

There might be questions that you don't know the answer to. That's okay - all you have to do is tell me.

Sometimes when we're talking there may be things I ask you which don't make a lot of sense because of the way I have asked the question. If that happens you can tell me you don't understand and I will ask you a different question.

There may be things I ask which you don't want to answer. That's okay too. All you have to do is tell me you want to pass. Then I'll go on to the next question.

As I said before, what I'd like to do today is find out a little bit about you and what its like in your family when you Mum/Dad isn't well. To help us, I had a think before I came to see you about some of the things that we could talk about. Maybe we would start with them and then

if we have missed anything that's important we can add them. The things I thought of are:

>>prompt sheet

(A bit about you, Your family, Your Mum /Dad and what happens when s/he is not well, Things that help when Mum/ Dad is not well, Messages for other children)

there are some questions I might ask you that I will know the answer to because I have already meet people in your family. For instance, I might ask you who lives in your house. That's because I want to make sure I ask everyone I meet the same questions. It also means I have a record of everything I need to know because in a few months time when come back to look at my notes, it might be difficult for me to remember things like who else lives in your house.

I would like to use this tape-recorder when we are talking to help me remember what you say. To make sure the tape is kept private. I won't use your names on it. I will use a code number instead. After I go away today, I will listen to and write down what we have talked about, but no else is allowed to listen to it. Is that OK? If you prefer, I can just write a few things down while we talk if you want. When I have made notes from the tape, I wipe them clean so there is nothing recorded on them. That way, no one else gets to hear what is on the tape. If you prefer, you can have the tape to keep.

You don't have to talk to me, it's up to you. What do you think?

Ask young person to sign consent form

Set up tape recorder asking young person to nominate code

INTRODUCTION TO INTERVIEW

I have brought lots of paper and pens with me. When I have been interviewing younger children I have asked them to do some drawings and diagrams of the things we have talked about. This has been quite a good thing to do because it means I have some drawings to decorate the book I am intending to write at the end of the project. I don't know if you like drawing., so I have brought some paper and pens just in case. If you prefer, we can just talk.

A BIT ABOUT YOU

I know you are.....years old, but what is your date of birth?

What are you doing at the moment?

>Are you at school/college/working

>How long have you been doing that?

>What is it like?

What do you like doing when you are not at school/college/ work?

YOUR FAMILY

Who lives in your house?

➤ Do you have any brothers and sisters? What age are they?

Is there anyone else in your family who does not live in your house at the moment?

➤ *Brothers and sisters ?*

What things do your family like doing at weekends/holidays/in the evening?

If you were telling someone else who hadn't met your family before what they were like, is there anything else you would want to tell them?

YOUR MUM/DAD

Next I thought we might talk a little about your Mum/Dad. First, I'd like to find out what your Mum/Dad is like generally.

General

If you were describing your Mum/Dad to a friend who had not met her/him before, what would you tell them?

- You might want to say something about what she's like
- What does she look like?
- What does she like doing?

Beliefs About Parent's Health

Now I'd like to talk about your Mum/Dad not being very well.

Do you remember what age you were when you first noticed that your Mum/Dad wasn't well?

- ***Do you remember what else was happening?***
- ***Do you remember what school you were at?***

*******Use timeline*******

Why did you think s/he wasn't well?

How did you find out?

How did you feel about it?

Now that you're a bit older and know a bit more, what would you tell other children/young people about why your Mum/Dad's is poorly sometimes?

Do you think it's serious or not?

What Happens When Mum/Dad Is Not Well:

At the moment, what happens when Mum/Dad is not well?

What happens on weekdays ?
What happens on weekends ?
What happens during holidays?

- >What does your Mum/Dad do?
- >What do your brothers and sisters do ?
- >What does other parent do ?
- > What do you do?

How do you feel when these things happen?
Which of the feelings you have told me about do you show/not show people?

IF NEGATIVE EMOTION >

What do you do to make yourself feel better?

IF UNSURE

Can you think of anything that might make you feel better?

Retrospective Data

Now I would like to do is spend a bit of time talking about what has happened when your Mum/Dad isn't well from as far back as you remember until now. The point is to find out about how things have changed as you have got older. To help you do this, I thought we could use something called a timeline. (Explain timeline).

Either you or I can write on the time line while we talk.

So when your Mum/Dad first became ill what difference did it make to

- **School days**
 - >What did your Mum/Dad do?
 - >What did your brothers and sisters do
 - >What did other parent do?
- **Weekends**
 - >repeat probes
- **Holidays**
 - > repeat probes

Then continue along timeline using same probes until get to present day.

How did you feel when these things happen?

What did you do to make yourself feel better?

At the moment, how often would you say your mum was unwell?

****use scale****

Meeting Other People

Have you ever met anyone else who had a Mum or Dad who was sometimes not very well like your Mum/Dad?

If yes,

What was that like? How did you feel?

If no,

Would like to? Why?

THINGS THAT HELP

First, I would like to talk about things you do. Then we'll talk about things other people do.

Things You Do

Is there anything you do that helps *you feel* better when your Mum/dad is not well?

Is there anything you do *to help other people* in your family when your Mum /Dad is not well?

Things Other People Do

Draw diagram of people that help.

Does anyone else do anything that *helps you* when Mum/Dad is not well?

Does anyone else do anything to *help other people in your family* when Mum/Dad is not well?

Is There Anything Your Mum Does That Helps Her?

To feel better?

In some other way?

HELP WANTED

Is there any other help you would like for you or your Mum/dad or anyone else in your family?

MESSAGES FOR OTHER YOUNG PEOPLE

If I was writing a book or leaflet for children and teenagers who have just found out that their Mum or Dad, is there any message you would want to pass on to them?

CLOSURE

- **Is there anything we have not talked about that you want to tell me?**
- **Thanks**
- **Remind will send them a summary/book about the project**
- **Use form:**
 - Ask them to nominate an alternative name
 - Check what they want returned
- **Discuss what they are doing for the rest of the day**

Appendix 18

Study 2: Visual aids used during interviews

A BIT ABOUT YOU

YOUR FAMILY

**YOUR DAD AND WHAT HAPPENS
WHEN HE IS NOT WELL**

**THINGS THAT HELP WHEN DAD IS
NOT WELL**

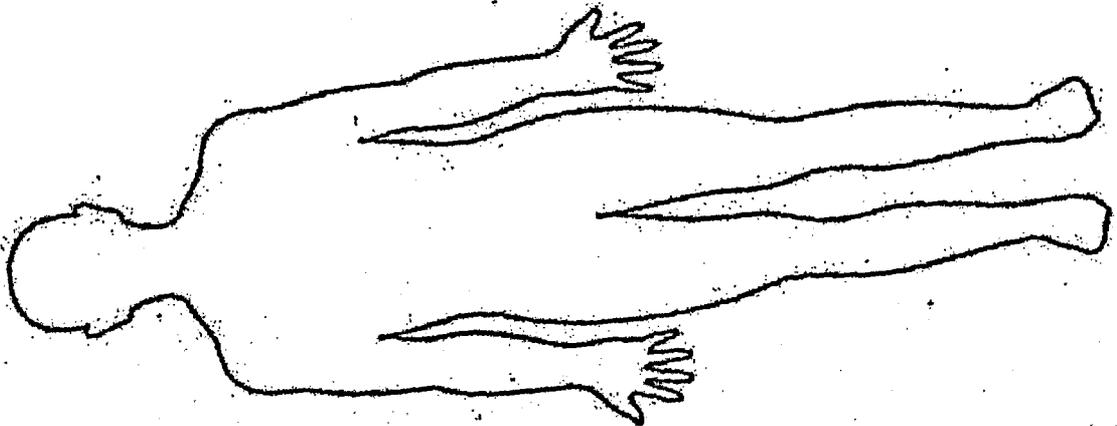
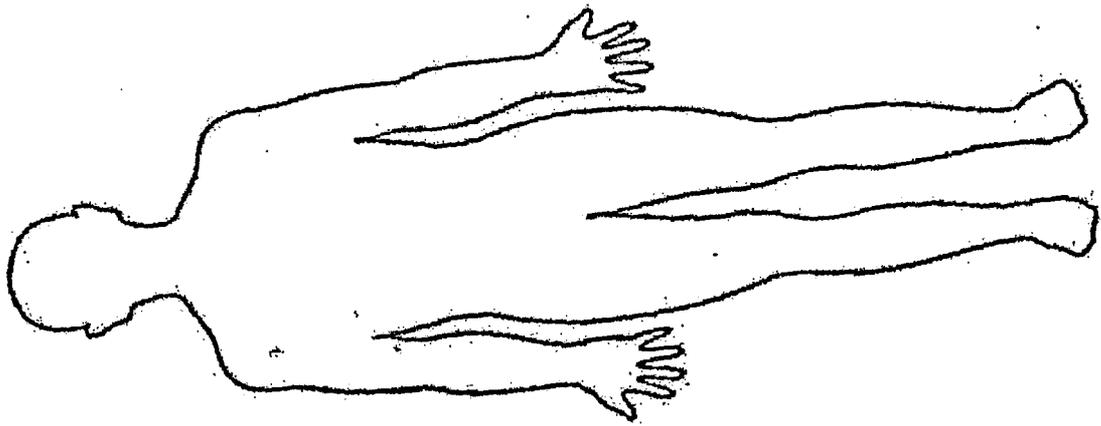
**MESSAGES FOR OTHER CHILDREN
AND YOUNG PEOPLE**

A BIT ABOUT ME

MY FAMILY

MY MUM AND WHAT HAPPENS WHEN SHE'S NOT WELL

THINGS THAT HELP



HOW OFTEN ?

↓
NEVER

↓
ALL THE TIME

A MESSAGE

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Appendix 19

Study 2: Young people's consent form

YOUNG PERSON'S CONSENT FORM

The project on 'When Mum or Dad feels ill'

Tick a box(es)

Have you read the project information sheet?.....

Yes

No

Do you know what taking part in the project means?.....

Yes

No

Do you understand that you can change your mind about.....
taking part at any time?

Yes

No

Do you understand Suzanne will keep everything you say private?.....
-it's up to you if you want to tell other people what you
have talked about

Yes

No

Do you want to take part in the project?.....

Yes

No

Please write your name here:.....

Please write the date here:.....



Thanks

Appendix 20

Study 2: Parent's consent form

PARENT'S CONSENT FORM

The project on 'When Mum or Dad feels ill'

Parent's name:.....

Child's name:.....

Child's date of birth:.....

Have you read the project information sheet?

Tick a box

Yes No

Do you know what taking part in the project means for your child?

Tick a box

Yes No

Do you understand that everything your child discusses with the researcher is confidential?

Tick a box

Yes No

Do you understand that information gathered during the project will be used to write research articles and reports?

Tick a box

Yes No

Are you happy for your child to take part in the research project?

Tick a box

Yes No

Parents' signature:.....**Date:**.....

Appendix 21

Study 2: Contract used to explain confidentiality to children

The project on 'When Mum or Dad feels ill'

To

I promise that I will keep everything we talk about private.

I will not tell anybody what we have talked about, unless you ask me to.

I will include things we have talked about in the books and reports I write about the project, but I will not use your real name in any of the books or reports.

The only time I will break this promise is if you tell me something that makes me worried that someone has done something to hurt you. If that happens, I will need to tell other people what you have said so that I can get you some help.

Signed.....

Date.....

Appendix 22

**Study 2: Form recording young person's decision regarding disposal
of research materials**

WHAT HAPPENS NEXT ?

Code:.....

Date:.....

When Suzanne writes books and reports about the project she will not use your real name. What name would you like her to use instead?

.....

What would you like Suzanne to do with the things you have put in your box?

Please tick one of the following:

- Return everything in the box to me**

- Return some of the things in the box**
Please write a list of the things you would like returned:
.....
.....
.....
.....

- Do not send anything from the box back to me**

Appendix 23

Study 3 & 4: Power analyses to determine sample size

The one sample test of proportion on parents' anxiety at case level (Snaith and Zigmond's criteria)

Power for a test of the null hypothesis

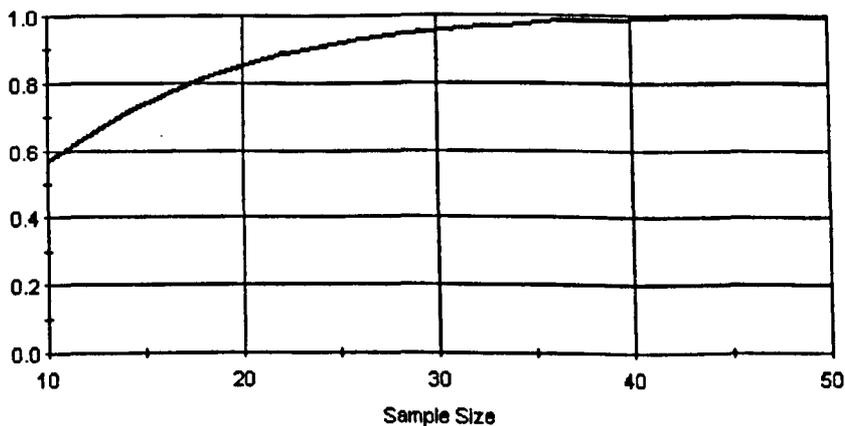
One goal of the proposed study is to test the null hypothesis that the proportion positive in the population is 0.33. The criterion for significance (α) has been set at 0.050. The test is 2-tailed, which means that an effect in either direction will be interpreted.

With the proposed sample size of 24 the study will have power of 90.9% to yield a statistically significant result.

This computation assumes that the proportion positive in the population is 0.66. The observed value will be tested against a theoretical value (constant) of 0.33

This effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.

Power as a Function of Sample Size



Precision for estimating the effect size

A second goal of this study is to estimate the proportion positive in the population. Based on these same parameters and assumptions the study will enable us to report the this value with a precision (95.0% confidence level) of approximately plus/minus 0.18 points.

For example, an observed proportion of 0.66 would be reported with a 95.0% confidence interval of 0.46 to 0.82.

The precision estimated here is the approximate expected (i.e. average) precision. Precision will vary as a function of the observed proportion (as well as sample size), and in any single study will be narrower or wider than this estimate.

The one sample test of proportion on parents' depression at case level (Snaith and Zigmond's criteria)

Power for a test of the null hypothesis

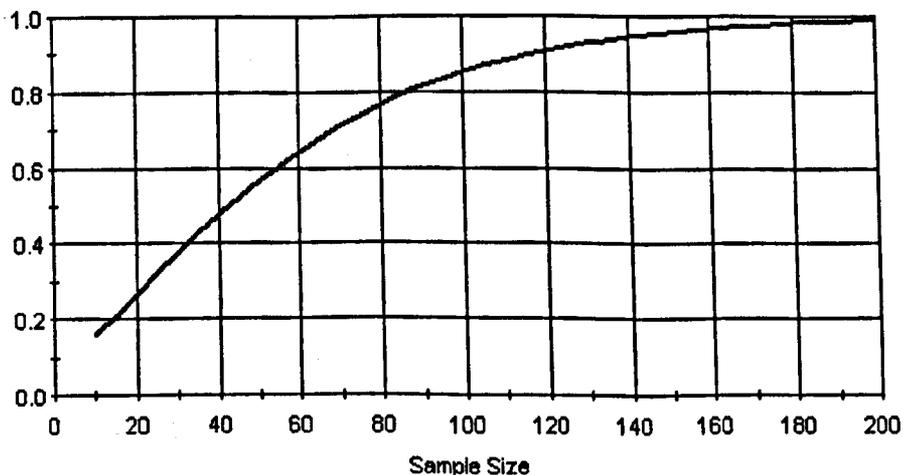
One goal of the proposed study is to test the null hypothesis that the proportion positive in the population is 0.11. The criterion for significance (α) has been set at 0.050. The test is 2-tailed, which means that an effect in either direction will be interpreted.

With the proposed sample size of 117 the study will have power of 90.1% to yield a statistically significant result.

This computation assumes that the proportion positive in the population is 0.22. The observed value will be tested against a theoretical value (constant) of 0.11

This effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.

Power as a Function of Sample Size



Precision for estimating the effect size

A second goal of this study is to estimate the proportion positive in the population. Based on these same parameters and assumptions the study will enable us to report the this value with a precision (95.0% confidence level) of approximately plus/minus 0.07 points.

For example, an observed proportion of 0.22 would be reported with a 95.0% confidence interval of 0.15 to 0.30.

The precision estimated here is the approximate expected (i.e. average) precision. Precision will vary as a function of the observed proportion (as well as sample size), and in any single study will be narrower or wider than this estimate.

The one sample test of proportion on parent-reported SDQ case level difficulties (probable and definite)

Power for a test of the null hypothesis

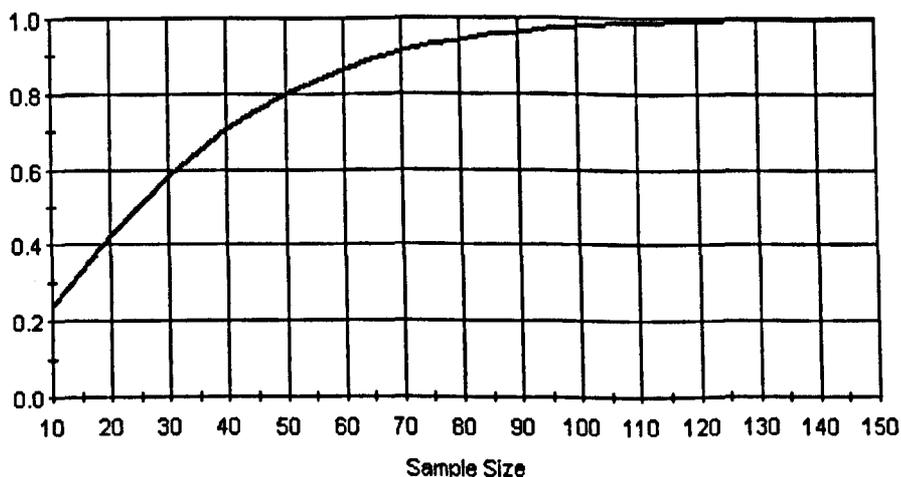
One goal of the proposed study is to test the null hypothesis that the proportion positive in the population is 0.17. The criterion for significance (alpha) has been set at 0.050. The test is 2-tailed, which means that an effect in either direction will be interpreted.

With the proposed sample size of 68 the study will have power of 90.3% to yield a statistically significant result.

This computation assumes that the proportion positive in the population is 0.34. The observed value will be tested against a theoretical value (constant) of 0.17

This effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.

Power as a Function of Sample Size



Precision for estimating the effect size

A second goal of this study is to estimate the proportion positive in the population. Based on these same parameters and assumptions the study will enable us to report the this value with a precision (95.0% confidence level) of approximately plus/minus 0.11 points.

For example, an observed proportion of 0.34 would be reported with a 95.0% confidence interval of 0.24 to 0.46.

The precision estimated here is the approximate expected (i.e. average) precision. Precision will vary as a function of the observed proportion (as well as sample size), and in any single study will be narrower or wider than this estimate.

The one sample test of proportion on self-reported SDQ case level difficulties (probable and definite)

Power for a test of the null hypothesis

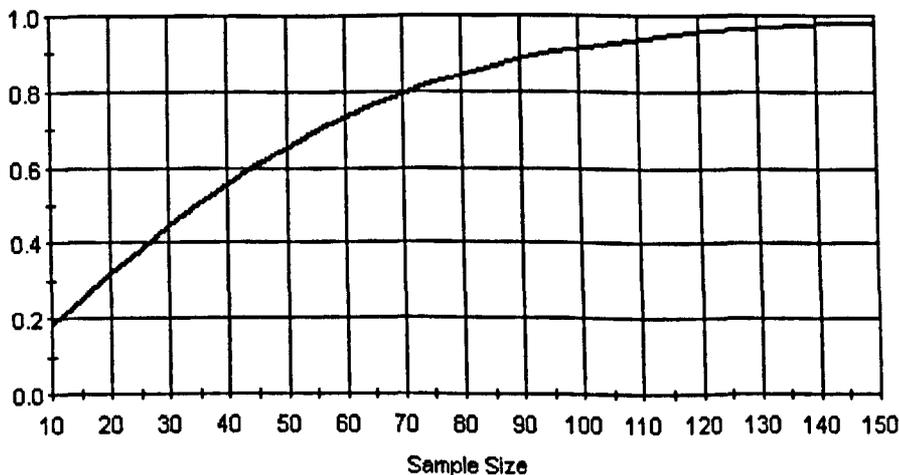
One goal of the proposed study is to test the null hypothesis that the proportion positive in the population is 0.13. The criterion for significance (alpha) has been set at 0.050. The test is 2-tailed, which means that an effect in either direction will be interpreted.

With the proposed sample size of 96 the study will have power of 90.3% to yield a statistically significant result.

This computation assumes that the proportion positive in the population is 0.26. The observed value will be tested against a theoretical value (constant) of 0.13

This effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of research.

Power as a Function of Sample Size



Precision for estimating the effect size

A second goal of this study is to estimate the proportion positive in the population. Based on these same parameters and assumptions the study will enable us to report the this value with a precision (95.0% confidence level) of approximately plus/minus 0.09 points.

For example, an observed proportion of 0.26 would be reported with a 95.0% confidence interval of 0.18 to 0.36.

The precision estimated here is the approximate expected (i.e. average) precision. Precision will vary as a function of the observed proportion (as well as sample size), and in any single study will be narrower or wider than this estimate.

Appendix 24

Study 3: Screening questionnaire and information sheet



INFORMATION SHEET (NACC members)

The research project on IBD and family life

Thank you for contacting me to say you are interested in the survey about inflammatory bowel disease (also known as ulcerative colitis and Crohn's disease) and family life. This leaflet provides you with some information on the research so that you can decide whether you want to take part.

What is the purpose of the research?

The purpose of the research is to find out:

- ❖ how IBD affects family life.
- ❖ whether there is a need to improve the help and support offered to families.

Why is the research important?

This is the first time any such research has been carried out. The findings will provide useful information to people who are in a position to offer support to people with IBD.

What does taking part involve?

Taking part would involve completing the short questionnaire attached to this letter. This should only take five minutes of your time. The purpose of the questionnaire is to find out about your health and family circumstances. For many people, this is all that taking part will involve. However, some people will be selected at random to receive two more questionnaires:

- a questionnaire *for you* about every day life and any help you would like from services.
- a questionnaire *for child/ren* aged 11- 16 years about everyday life for them and any help they would like.

Parents are asked to take part in the survey even if their child is unable, or does not wish, to complete a questionnaire.

Who is taking part?

Members of NACC who have a child aged 16 years or younger are invited to take part. Invitations are also being sent to patients in four gastroenterology clinics in England.

What will happen to the information?

The information you provide will be treated as strictly confidential and will only be used for the purposes of this research study. A summary of the survey findings will be:

- sent to NACC.
- sent to staff in gastroenterology clinics which have assisted with the study.
- included in journal articles written for professionals who support patients with IBD.
- included in a report submitted to the University of York as part of my work towards a PhD.

Under no circumstances will your name, or any other information that might identify you, be included in reports.

Who is carrying out the research

Suzanne Mukherjee, a PhD student at the Department of Health Studies, University of York, is carrying out the research. Suzanne is an experienced researcher whose previous work includes a research project for NACC.

Do I have to take part?

No, you do not have to take part in the survey. Participation is voluntary. Your decision will not affect the services you receive from NACC or any other organisation.

What happens next?

If you are willing to take part in this research, please complete the attached questionnaire and return it to me in the pre-paid envelope.

If you would like any further information on the research before deciding, please contact me at the address given at the end of this form.

With thanks for your help.

Suzanne Mukherjee

Suzanne Mukherjee, Department of Health Sciences, University of York, 1st Floor Alcuin Teaching Building, FREEPOST NEA 12996, York, YO10 5ZZ.
Tel: 01904 434118 Email: Skmw1@york.ac.uk

SECTION C: TO BE COMPLETED BY EVERYONE

CODE						
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If you have any other comments, please feel free to write them in the box below.

THE UNIVERSITY *of York*

QUESTIONNAIRE ON
HEALTH AND FAMILY CIRCUMSTANCES

The research project on IBD and family life

This short questionnaire asks a few questions about your health and family circumstances.

I would be very grateful if you would complete the form and return it to Suzanne Mukherjee, University of York, in the pre-paid envelope attached.

Thank you for taking the time to complete this form. Please return it to me in the pre-paid envelope attached.



If you would like to talk to me about the research, telephone the number below between 9.00 am and 5.30 pm Monday to Friday, or write to Suzanne Mukherjee, Department of Health Sciences, University of York, 1st Floor Alcuin Teaching Building, FREEPOST NEA 12996, York, YO10 5ZZ
Tel: 01904 434118 Email: Skmw1@york.ac.uk

Thank-you

Appendix 25

Study 3: Information sheet and questionnaire for parents



INVITATION

The survey on IBD and family life April 2002 (2)

Dear Parent

Thank you for returning the questionnaire sent earlier in the year asking about your health and family circumstances. I am writing now to invite you to take part in the second stage of the survey about inflammatory bowel disease (also known as ulcerative colitis and Crohn's disease) and family life. This leaflet provides some information so that you can decide whether you want to take part.

What is the point of the survey?

The overall aim in carrying out the survey is to make recommendations about the support needed by families in which a parent has inflammatory bowel disease (IBD). This is the first time such a survey has been carried out. It is an opportunity for you to tell others about the type of help you would like.

Why are you inviting me to take part ?

I am inviting patients from the gastroenterology clinic you attend, who have IBD and a child aged 16 years or younger, to take part in the survey. Parents invited to take part have been selected at random.

What will happen to the information?

Your response to the questionnaire will be put together with responses from other participants. This data will then be analysed and a summary of the findings sent to all families who take part in the research. A summary of the findings will also be:

- sent to staff in gastroenterology clinics who have assisted with the study
- included in articles written for professionals who support patients with IBD
- included in a report submitted to the University of York as part of my work towards a PhD

All the information you provide will be treated as strictly confidential and will only be used for the purposes of this research study. To help maintain your confidentiality, you have been assigned a code number and you do not need to put your name on the form. Under no circumstances will your name, or any other information that might identify your family, be included in reports about the research.

Who is carrying out the research

Suzanne Mukherjee, a PhD student at the Department of Health Sciences, University of York, is carrying out the research. Suzanne is an experienced researcher whose previous work includes a research project for the National Association of Colitis and Crohn's Disease (NACC).

What does the survey ask about?

The survey asks parents with IBD about:

- Their health and how they have been feeling recently
- Any difficulties they have experienced as a parent due to IBD
- The support they receive and/or would like from others
- Their child(ren)'s strengths and difficulties
- Their family circumstances

It also asks children between the age of 11 and 16 about:

- Their views on their Mum/ Dad's health
- Things they do to help
- Social, school and family life
- What they see as their strengths and difficulties
- Any help they might like

Why are you asking these questions?

Over the last year I have met with 24 parents who have IBD and their children. They told me about the difference IBD has made to their lives and the help they would like. The questions in the survey are designed to find out whether other people have similar views.

Do I have to take part?

No, you do not have to take part in the survey. Participation is voluntary. Your decision will not affect the treatment or services you receive in any way.

What happens next?

If you are willing to take part in the survey, I would appreciate it if you could do two things:

- Please complete the questionnaire for parents and return it to me in the pre-paid envelope provided
- Please pass on the enclosed envelope entitled 'Survey for Young People' to every child in your family aged between 11 and 16 years. This envelope contains an information leaflet about the research and a short questionnaire. Your child can then decide whether s/he wants to take part in the survey. Participation is voluntary. Your child does not have to take part in the survey and his/her decision will not affect the treatment or services you receive in any way.

Thank you for reading this leaflet

Suzanne Mukherjee

For further information on the research, or to discuss any of the issues raised by it, please contact:

Suzanne Mukherjee, Department of Health Sciences, University of York, 1st Floor Alcuin Teaching Building,
FREEPOST NEA 12996, York, YO10 5ZZ.

Tel: 01904 434118 Email: Skmw1@york.ac.uk

CODE						
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If you do not want to fill this questionnaire in, please tick here and return it in the envelope provided.

QUESTIONNAIRE FOR PARENTS

July 2002 (3)

The research project on IBD and family life

Thank you for agreeing to take part in this survey. The responses that you give will help me find out what help should be provided to parents with inflammatory bowel disease (IBD) who have children living at home.

This questionnaire asks parents who have IBD about:

- Your health and how you have been feeling recently
- Any difficulties you have experienced as a parent due to IBD
- The support you receive and/or would like from others
- Your child(ren)'s strengths and difficulties
- Your family circumstances

The survey is based on a small research project in which parents described the impact IBD was having on their everyday life. The questions are designed to find out if other parents are having a similar experience. Some of the questions may seem personal. However, these questions are important because they will help identify the kinds of support that should be offered to people with IBD and their families.

All the information you provide will be treated as strictly confidential. To make sure your privacy is respected, you have been assigned a code number.

Instructions on filling in the form are given for each section. For most questions you simply have to tick a box or circle an answer. It will take about 30 minutes to fill in the form.

It would help me if you could answer all the questions. However, if you do not wish to answer some of the questions you can leave them out.

THANK YOU

Suzanne Mukherjee

SECTION 1 : YOUR HEALTH

This first section asks about:

- Your health in general
- Your inflammatory bowel disease
- Your mood over the *past week*

Your health in general

1. In general would you say your health is ... (Please ✓ a box)

Excellent

Very good

Good

Fair

Poor

2. Apart from IBD, do you have any other long term illnesses, health problems, or disabilities which limit your daily activities or the work you can do? (Please ✓ a box)

No

Yes *If yes, please state what they are below:*

.....

.....

.....

.....

Background information on inflammatory bowel disease

1. Approximately how many years have you had symptoms of IBD?

.....years

2. In total, how many times have you stayed *overnight in hospital* for tests, treatment or surgery due to IBD? (Please ✓ a box)

Never

1-2 times

3-5 times

6-10 times

11 times or more

3. **During the last year**, have you needed to stay *overnight in hospital* for tests, treatment or surgery due to IBD? (Please ✓ a box)

No.....

Yes.....

4. **In total**, how many times have you had surgery due to IBD? (Please ✓ a box)

Never

Once

2-3 times

4-5 times

6 times or more

5. **During the last year**, have you had surgery due to IBD?

(Please ✓ a box)

No.....

Yes.....

6. Do you attend a hospital outpatient clinic for your IBD?

No.....

Yes.....

If yes, during the last year, approximately how often have you attended the outpatient clinic? (Please ✓ a box)

1-2 times

3-5 times

6-11 times

Once a month

Twice a month

7. **During the last year**, have you been prescribed regular medication for your IBD?

(Please ✓ a box)

No.....

Yes.....

8. **During the last year**, have you been prescribed steroids? (Please ✓ a box)

No.....

Yes.....

9. **During the last year**, have you been prescribed Azathioprine (Immuran)?

(Please ✓ a box)

No.....

Yes.....

Your health over the past two weeks

The following questions are designed to find out how you have been feeling during the last 2 weeks. You will be asked about symptoms you have been having as a result of your inflammatory bowel disease, the way you have been feeling in general, and how your mood has been.

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

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

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

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

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

- a) A great deal of difficulty, activities made impossible.....
- b) A lot of difficulty.....
- c) A fair bit of difficulty.....
- d) Some difficulty.....
- e) A little difficulty.....
- f) Hardly any difficulty.....
- g) No difficulty, the bowel problems did not limit sports or leisure activities.....

How often during the last 2 weeks have you been troubled by pain in the abdomen? Please choose an option from:

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

How often during the last 2 weeks have you felt depressed or discouraged? Please choose an option from:

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

Overall, in the last 2 weeks, how much of a problem have you had with passing large amounts of gas? Please choose an option from:

- a) A major problem.....
- b) A big problem.....
- c) A significant problem.....
- d) Some trouble.....
- e) A little trouble.....
- f) Hardly any trouble.....
- g) No trouble.....

Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be? Please choose an option from:

- a) A major problem.....
- b) A big problem.....
- c) A significant problem.....
- d) Some trouble.....
- e) A little trouble.....
- f) Hardly any trouble.....
- g) No trouble.....

How often during the last 2 weeks have you felt relaxed and free of tension? Please choose an option from:

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

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

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

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

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

Your mood over the past week

This section is designed to help know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling **in the past week**. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':

Most of the time.....
 A lot of the time.....
 Time to time, occasionally.....
 Not at all.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

I feel as if I am slowed down:

Nearly all the time.....
 Very often.....
 Sometimes.....
 Not at all.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

I still enjoy the things I used to enjoy:

Definitely as much.....
 Not quite so much.....
 Only a little.....
 Hardly at all.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all.....
 Occasionally.....
 Quite often.....
 Very often.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly.....
 Yes, but not too badly.....
 A little, but it doesn't worry me.....
 Not at all.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

I have lost interest in my appearance:

Definitely.....
 I don't take so much care as I should.....
 I may not take quite as much care.....
 I take just as much care as ever.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

I can laugh and see the funny side of things:

As much as I always could.....
 Not quite so much now.....
 Definitely not so much now.....
 Not at all.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

I feel restless as if I have to be on the move:

Very much indeed.....
 Quite a lot.....
 Not very much.....
 Not at all.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

Worrying thoughts go through my mind

A great deal of the time.....
 A lot of the time.....
 From time to time but not too often.....
 Only occasionally.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

I look forward with enjoyment to things:

As much as I ever did.....
 Rather less than I used to.....
 Definitely less than I used to.....
 Hardly at all.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

I feel cheerful:

Not at all.....
 Not often.....
 Sometimes.....
 Most of the time.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

I get sudden feelings of panic:

Very often indeed.....
 Quite often.....
 Not very often.....
 Not at all.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

I can sit at ease and feel relaxed:

Definitely.....
 Usually.....
 Not often.....
 Not at all.....

<input type="checkbox"/>	<input checked="" type="checkbox"/>

I can enjoy a good book or radio or TV programme:

Often.....
 Sometimes.....
 Not often.....
 Very seldom.....

<input checked="" type="checkbox"/>	<input type="checkbox"/>

Do not write below this line

SECTION 2: DIFFICULTIES EXPERIENCED AS A PARENT

In the previous research project on IBD, some parents mentioned they had experienced difficulties with parenting tasks. The purpose of this section is to find out how many other people are having similar experiences.

Listed below are a number of activities which a parent does and which may be affected by having a chronic illness. There are three separate sections for children of different ages. *Please complete all the sections that apply to you at the moment.* For example, if you have a child under one year age, you would complete Section 1. Infancy. If you have a child aged between 1 and 10 years, you would complete Section 2. Childhood. If you have a child aged between 11 and 16 years, you would complete Section 3. Adolescence.

For each statement, please state how much difficulty you have had with the task over the past year by circling the answer that applies to you. If a statement does not apply to you because you are not involved in this activity, please tick 'Not Applicable'. Some items are repeated across age groups.

1. INFANCY (BIRTH TO 1 YEAR)

Do you have a child aged 0-1 years?

Yes.... *If Yes, please complete this section*

No..... *If No -please go to Section 2. Childhood*

	No difficulty & requiring no effort	Mild difficulty requiring some effort	Moderate difficulty requiring effort	Severe difficulty requiring great effort	Not applicable - not involved in task
1. Breast or bottle feeding.....	0	1	2	3	N/A
2. Bathing.....	0	1	2	3	N/A
3. Changing nappies.....	0	1	2	3	N/A
4. Dressing.....	0	1	2	3	N/A
5. Cuddling/hugging/comforting.....	0	1	2	3	N/A
6. Picking up your baby	0	1	2	3	N/A
7. Putting down your baby	0	1	2	3	N/A
8. Following a nap/sleep routine.....	0	1	2	3	N/A
9. Giving medications to your baby.....	0	1	2	3	N/A
10. Taking care of your baby's needs.....	0	1	2	3	N/A
11. Using a baby car seat	0	1	2	3	N/A
12. Feeding solid foods.....	0	1	2	3	N/A
13. Putting up/down crib sides.....	0	1	2	3	N/A
14. Putting child in highchair.....	0	1	2	3	N/A
15. Playing with your baby	0	1	2	3	N/A
16. Disciplining your baby & following through...	0	1	2	3	N/A
17. Reading cues for hunger, sleep etc.	0	1	2	3	N/A
18. Reading cues when sick (e.g., pulling on ears)	0	1	2	3	N/A

Continued on next page

1. INFANCY (BIRTH TO 1 YEAR) *continued*

	No difficulty requiring no effort	Mild difficulty requiring some effort	Moderate difficulty requiring effort	Severe difficulty requiring great effort	Not applicable - not involved in task
19. Helping to talk.....	0	1	2	3	N/A
20. Helping to walk/ crawl.....	0	1	2	3	N/A
21. Providing safety measures (e.g. gates, locks etc.)..	0	1	2	3	N/A
22. Helping your baby to drink from a cup.....	0	1	2	3	N/A
23. Going to doctor/dentist.....	0	1	2	3	N/A
24. Providing transportation.....	0	1	2	3	N/A
25. Shopping for baby's needs.....	0	1	2	3	N/A
26. Performing household chores	0	1	2	3	N/A
27. Visiting extended family (e.g. grandparents) or friends.....	0	1	2	3	N/A
28. Brushing baby's gums/teeth.....	0	1	2	3	N/A
29. Taking a holiday with family	0	1	2	3	N/A
30. Talking/ listening to baby	0	1	2	3	N/A
31. Help with toilet training	0	1	2	3	N/A
32. Reading books.....	0	1	2	3	N/A
33. Going to the playground.....	0	1	2	3	N/A
34. Going to the zoo, museums with your baby.....	0	1	2	3	N/A
35. Going to parent/child classes (e.g. crafts, music)...	0	1	2	3	N/A
36. Scheduling bedtime activities.....	0	1	2	3	N/A
37. Providing for financial needs.....	0	1	2	3	N/A
38. Having a friend over to play	0	1	2	3	N/A
39. Other (please list below).....	0	1	2	3	N/A

2. CHILDHOOD (1 to 10 years)

Do you have a child aged 1 to 10 years?

Yes... *If Yes, please complete this section*

No..... *If No -please go to Section 3. Adolescence*

	No difficulty requiring no effort	Mild difficulty requiring some effort	Moderate difficulty requiring effort	Severe difficulty requiring great effort	Not applicable - not involved in task N/A
1. Help with feeding.....	0	1	2	3	N/A
2. Help with drinking.....	0	1	2	3	N/A
3. Help with running, skipping, and hopping.....	0	1	2	3	N/A
4. Help with learning letters and numbers.....	0	1	2	3	N/A
5. Holding/hugging/comforting.....	0	1	2	3	N/A
6. Help with talking, speaking sentences.....	0	1	2	3	N/A
7. Selecting a preschool/school.....	0	1	2	3	N/A
8. Following a sleep routine.....	0	1	2	3	N/A
9. Providing transportation.....	0	1	2	3	N/A
10. Disciplining your child and following through.....	0	1	2	3	N/A
11. Using a car seat/buckle.....	0	1	2	3	N/A
12. Taking a holiday with family.....	0	1	2	3	N/A
13. Playing with your child indoors.....	0	1	2	3	N/A
14. Playing with your child outdoors.....	0	1	2	3	N/A
15. Arranging for a babysitter.....	0	1	2	3	N/A
16. Following a bed time routine.....	0	1	2	3	N/A
17. Taking care of any illnesses/medical needs	0	1	2	3	N/A
18. Safety issues (e.g. gates, poisons).....	0	1	2	3	N/A
19. Going to the doctor/dentist.....	0	1	2	3	N/A
20. Helping to dress.....	0	1	2	3	N/A

Continued on next page

2. CHILDHOOD (1- 10 YEARS) *continued*

	No difficulty & requiring no effort	Mild difficulty requiring little effort	Moderate difficulty requiring effort	Severe difficulty requiring great effort	Not applicable - not involved in task
21. Helping to bathe.....	0	1	2	3	N/A
22. Caring for more than one child.....	0	1	2	3	N/A
23. Performing household chores.....	0	1	2	3	N/A
24. Providing for financial needs.....	0	1	2	3	N/A
25. Shopping for child's needs.....	0	1	2	3	N/A
26. Helping to brush teeth.....	0	1	2	3	N/A
27. Visiting extended family (e.g., grandparents) & friends.....	0	1	2	3	N/A
28. Allowing child's friends to visit.....	0	1	2	3	N/A
29. Participating in/attending preschool/school.....	0	1	2	3	N/A
30. Talking/listening to child.....	0	1	2	3	N/A
31. Day trips and outings.....	0	1	2	3	N/A
32. Reading to child.....	0	1	2	3	N/A
33. Hosting a birthday party.....	0	1	2	3	N/A
34. Providing meals.....	0	1	2	3	N/A
35. Helping child develop writing, reading, & math skills.....	0	1	2	3	N/A
36. Assigning household chores & enforcing.....					
37. Helping to maintain a good sleep routine.....	0	1	2	3	N/A
38. Assisting in child's homework.....	0	1	2	3	N/A
39. Providing health education.....	0	1	2	3	N/A
40. Allowing for child's privacy.....	0	1	2	3	N/A
41. Other (please list below).....	0	1	2	3	N/A

3. ADOLESCENCE (11 -16 YEARS)

Do you have a child aged 11-16 years?

No

Yes

If Yes, please complete this section

	No difficulty & requiring no effort	Mild difficulty requiring some effort	Moderate difficulty requiring effort	Severe difficulty requiring great effort	Not applicable - not involved in task
1. Providing meals.....	0	1	2	3	N/A
2. Providing transportation.....	0	1	2	3	N/A
3. Taking a holiday with family.....	0	1	2	3	N/A
4. Making sure child uses a seat belt.....	0	1	2	3	N/A
5. Hugging/comforting.....	0	1	2	3	N/A
6. Arranging for a babysitter.....	0	1	2	3	N/A
7. Caring for more than one child.....	0	1	2	3	N/A
8. Helping with clothes selection.....	0	1	2	3	N/A
9. Setting a curfew.....	0	1	2	3	N/A
10. Disciplining your child & following through.....	0	1	2	3	N/A
11. Going to the doctor/dentist.....	0	1	2	3	N/A
12. Taking care of medical needs.....	0	1	2	3	N/A
13. Performing household chores.....	0	1	2	3	N/A
14. Shopping for child's needs.....	0	1	2	3	N/A
15. Providing for financial needs.....	0	1	2	3	N/A
16. Working with child to develop writing, reading & math skills.....	0	1	2	3	N/A
17. Talking about dating.....	0	1	2	3	N/A
18. Safety issues (e.g., accident, poisons).....	0	1	2	3	N/A
19. Helping to maintain dental hygiene.....	0	1	2	3	N/A
20. Assisting in child's homework.....	0	1	2	3	N/A
21. Helping to maintain a sleep routine.....	0	1	2	3	N/A
22. Helping to making choices about school (e.g., selecting school, subjects to study).....	0	1	2	3	N/A
23. Providing health education.....	0	1	2	3	N/A
24. Visiting extended family (e.g., grandparents) & friends.....	0	1	2	3	N/A
25. Allowing child's friends to visit.....	0	1	2	3	N/A
26. Participating in/attending school activities with child.....	0	1	2	3	N/A
27. Talking/listening to child.....	0	1	2	3	N/A
28. Allowing for child's privacy.....	0	1	2	3	N/A
29. Assigning household chores and enforcing.....	0	1	2	3	N/A
30. Teaching child to drive.....	0	1	2	3	N/A
31. Planning for life after school.....	0	1	2	3	N/A
32. Hosting parties.....	0	1	2	3	N/A
33. Other (please list below).....	0	1	2	3	N/A

SECTION 3: SUPPORT FROM OTHERS

This section asks about:

- The support you receive from others in bringing up your child/children
- Help needed by you and your family

The support you receive from others

Listed below are people and groups that often are helpful to members of a family bringing up a child. This questionnaire asks you to indicate how helpful each source is to *your family*.

Please circle the response that best described how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle N/A (Not Available) response.

How helpful has each of the following been to you in terms of raising your child (ren):	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents.....	N/A	1	2	3	4	5
2. My spouse or partner's parents.....	N/A	1	2	3	4	5
3. My relatives.....	N/A	1	2	3	4	5
4. My spouse or partner's relatives.....	N/A	1	2	3	4	5
5. Spouse or partner.....	N/A	1	2	3	4	5
6. My friends.....	N/A	1	2	3	4	5
7. My spouse or partner's friends.....	N/A	1	2	3	4	5
8. My own children.....	N/A	1	2	3	4	5
9. Other parents.....	N/A	1	2	3	4	5
10. Work colleagues.....	N/A	1	2	3	4	5
11. Parent groups.....	N/A	1	2	3	4	5
12. Social groups/clubs.....	N/A	1	2	3	4	5
13. Church members/minister.....	N/A	1	2	3	4	5
14. My family doctor (GP)	N/A	1	2	3	4	5
15. Health visitor.....	N/A	1	2	3	4	5
16. Hospital based health professionals ... (hospital doctors, nurses etc.)	N/A	1	2	3	4	5
17. Nursery staff/ school teachers.....	N/A	1	2	3	4	5
18. Social service staff.....	N/A	1	2	3	4	5
19. Others (Please describe below)	N/A	1	2	3	4	5
20. Others (Please describe below)	N/A	1	2	3	4	5

Help needed by you and your family from services

Listed below are some of the things parents with IBD have said they need help with. I would like to know if you need help from services with these things, and whether or not you are getting help at the moment. By services I mean organisations such as health, education, social services, or voluntary groups who offer support to families.

For each statement please ✓ the box which best describes your situation.

Please read *all three* options before ticking a box.

I need	Need this but I am getting enough	Need this and <i>not</i> getting it	Not needed
help getting my child to and from school			
help with shopping			
help with housework			
help preparing meals			
someone to look after my child when I have hospital appointments			
someone to look after my child when I am in hospital overnight			
help contacting family in times of a medical emergency			
financial support to assist with prescriptions			
more than one toilet in our house			
access to disabled parking to make it easier to get to toilets quickly			
time to recover from treatment before being sent home from hospital			
home treatment for bowel rest and tube feeding so that I do not have to go into hospital			
information and advice on the effects of IBD on pregnancy			
information and advice on the effects of IBD on family life			
information and advice on ileostomies or an ileoanal 'pouch'			
information and advice on returning home after surgery			
a booklet which explains IBD to my child			
advice on explaining IBD to my child			
advice on stress management			
an opportunity to talk to a counsellor about coping with IBD			
an opportunity to talk to other parents with IBD			
My partner/husband/wife needs.....			
someone to talk to about me having IBD			
information and advice on IBD			
My family needs.....			
an opportunity to meet other families in a similar situation			

SECTION 4: YOUR CHILD'S STRENGTHS AND DIFFICULTIES

In the previous project, parents reported that their children responded in lots of different ways to them having IBD – sometimes positively, sometimes negatively.

The purpose of this section of the questionnaire is to ask parents how their children have been getting on over the last six months. It asks for your views on your child's strengths and difficulties.

The questionnaire is designed for parents who have children aged between 4 and 16 years of age. **Please complete a questionnaire for every child in your family aged between 4 and 16 years.**

If your child is under 4 years of age you do **not** need to complete this section. Please go to final section of the questionnaire on 'Section 5: Your family circumstances'.

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Strengths and Difficulties - Questionnaire 1

Child's age.....

Child's sex.....

For each item below, please mark the box for *Not True*, *Somewhat True* or *Certainly True*. It would help us if you answered all items as best you can even if you are not absolutely certain or the items seem daft!

Please give your answers on the basis of the child's behaviour over the last six months.

	Not true	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school, or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page

1. Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- Severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered 'No', please go to question 2.

If you have answered 'Yes', please answer the following questions about these difficulties:

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do these difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Does your child have any long term illnesses, health problems, or disabilities which limit his/her daily activities? (Please tick a box)

No..... Yes..... If yes, please state what they are below:

.....

.....

.....

If you have another child aged 4-16 years - please complete 'Strengths and Difficulties-Questionnaire 2' on the next page.

If you do not have another child aged 4-16 years - please go to 'Section 5:Your family circumstances'

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Strengths and Difficulties - Questionnaire 2

Child's age.....

Child's sex.....

For each item below, please mark the box for *Not True*, *Somewhat True* or *Certainly True*. It would help us if you answered all items as best you can even if you are not absolutely certain or the items seem daft! Please give your answers on the basis of the child's behaviour over the last six months.

	Not true	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school, or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page

1. Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- Severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered 'No', please go to question 2.

If you have answered 'Yes', please answer the following questions about these difficulties:

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do these difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Does your child have any long term illnesses, health problems, or disabilities which limit his/her daily activities? (Please tick a box)

No..... Yes..... If yes, please state what they are below:

.....

.....

.....

If you have another child aged 4-16 years - please complete 'Strengths and Difficulties-Questionnaire 3' on the next page.

If you do not have another child aged 4-16 years - please go to 'Section 5:Your family circumstances'



Strengths and Difficulties - Questionnaire 3

Child's age.....

Child's sex.....

For each item below, please mark the box for *Not True*, *Somewhat True* or *Certainly True*. It would help us if you answered all items as best you can even if you are not absolutely certain or the items seem daft! Please give your answers on the basis of the child's behaviour over the last six months.

	Not true	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school, or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continued on next page

1. Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- Severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered 'No', please go to question 2.

If you have answered 'Yes', please answer the following questions about these difficulties:

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do these difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Does your child have any long term illnesses, health problems, or disabilities which limit his/her daily activities? (Please tick a box)

No..... Yes..... If yes, please state what they are below:

.....

.....

.....

SECTION 5: FAMILY CIRCUMSTANCES

This last section asks for some background information on your family circumstances, including work and child care arrangements.

1. Which of the following describes *your* current work situation?

(Please ✓ one box only)

- Working full-time
- Working part-time
- Not Working

If you are working, please go straight to question 4

2. Are you.....

(Please ✓ one box only)

- Looking after home/family
- Retired
- Long term sick/disabled
- Student
- None of the above

3. Have you *ever* worked?

Yes

If Yes, please write how long it is since you last worked in months and years

Years Months

No

IF NO - please go straight to question 8

Questions 4 -7 refer to your current main job, or (if you are not working now) to your last main job.

4. Do (did) you work as an employee or are (were) you self-employed?

(Please ✓ one box only)

- Employee
- Self-employed with employees
- Self-employed/freelance without employees (go to question 7).....

5. For employees: indicate below how many people work (worked) for your employer at the place where you work (worked).

For self-employed: indicate below how many people you employ (employed). Go to question 7 when you have completed this question.

1-24

25 or more

6. Do (did) you supervise any other employees?

(A supervisor is responsible for overseeing the work of other employees on a day-to-day basis).

Yes..... No.....

7. Please tick one box to show which best describes the sort of work you do.

(If you are not working now, please tick a box to show what you did in your last job)

PLEASE TICK ONE BOX ONLY

Modern professional occupations

such as: teacher – nurse – physiotherapist - social worker - welfare officer
– artist – musician - police officer (sergeant or above) – software designer

1

Clerical and intermediate occupations

such as: secretary - personal assistant - clerical worker - office clerk –
call centre agent - nursing auxiliary - nursery nurse

2

Senior managers or administrators

(usually responsible for planning, organising and co-ordinating work and
for finance)

such as: finance manager - chief executive

3

Technical and craft occupations

such as: motor mechanic – fitter – inspector – plumber – printer –
tool maker – electrician – gardener - train driver

4

Semi-routine manual and service occupations

such as: postal worker - machine operative - security guard – caretaker -
farm worker - catering assistant – receptionist - sales assistant

5

Routine manual and service occupations

such as: HGV driver - van driver – cleaner – porter – packer –
sewing machinist – messenger - labourer-waiter/waitress - bar staff

6

Middle or junior managers

such as: office manager - retail manager - bank manager –
restaurant manager - warehouse manager - publican

7

Traditional professional occupations

such as: accountant – solicitor - medical practitioner – scientist -
civil/mechanical engineer

8

8. Which of the following qualifications do you have?

(Please ✓ all those that apply to you, or if not specified, the nearest equivalent)

- | | |
|---|---|
| <input type="checkbox"/> 1 + O Levels/CSEs/GCSEs (any grades) | <input type="checkbox"/> NVQ Level 1, Foundation GNVQ |
| <input type="checkbox"/> 5 + O Levels/5 + CSEs (grade 1)/5 + GCSEs (grades A-C), School Certificate | <input type="checkbox"/> NVQ Level 2, Intermediate GNVQ |
| <input type="checkbox"/> 1 + A Levels/AS Levels | <input type="checkbox"/> NVQ Level 3, Advanced GNVQ |
| <input type="checkbox"/> 2 + A Levels, 4 +AS Levels, Higher School Certificate | <input type="checkbox"/> NVQ Levels 4-5, HNC, HND |
| <input type="checkbox"/> First degree (e.g. BA, BSc) | <input type="checkbox"/> Other Qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexcel) |
| <input type="checkbox"/> Higher degree (e.g. MA, PhD, PGCE, post-graduate certificates/diploma) | <input type="checkbox"/> No Qualifications |

Do you have any of the following professional qualifications?

(✓ boxes that apply to you)

- | | |
|---|---|
| <input type="checkbox"/> No professional qualifications | <input type="checkbox"/> Qualified Dentist |
| <input type="checkbox"/> Qualified Teacher Status (for schools) | <input type="checkbox"/> Qualified Nurse, Midwife, Health Visitor |
| <input type="checkbox"/> Qualified Medical Doctor | <input type="checkbox"/> Other Professional Qualification |

9. Are you currently living with a partner/spouse?

Yes..... No..... **IF NO, please go to question 20**

10. Does your partner have any other long term illnesses, health problems, or disabilities which limits her/his daily activities or the work s/he can do?

(Please ✓ a box)

No.....

Yes..... *If yes, please state what they are below:*

.....
.....

11. The next question is about how you currently share household jobs with your partner/ husband/ wife. For each section, could you please say who mostly does this work.

a) Grocery shopping *(Please ✓ one box)*

Mostly self.....

Mostly spouse/partner.....

Shared.....

Paid help only.....

Other.....

b) Cooking (Please ✓ one box)

- Mostly self.....
- Mostly spouse/partner.....
- Shared.....
- Paid help only.....
- Other.....

c) Cleaning/hovering (Please ✓ one box)

- Mostly self.....
- Mostly spouse/partner.....
- Shared.....
- Paid help only.....
- Other.....

d) Washing and ironing (Please ✓ one box)

- Mostly self.....
- Mostly spouse/partner.....
- Shared.....
- Paid help only.....
- Other.....

e) Are there child(ren) aged 12 or under living in the household?

Yes..... No..... **IF NO, please go to question 12**

IF YES, Who is mainly responsible for looking after the child(ren)? Is it ...
(Please ✓ one box only)

- Mainly you.....
- Mainly your husband/wife/partner.....
- Jointly with your husband/wife/partner.....
- Someone else.....

12. Which of the following describes your partner's current work situation?

(please ✓ one box only)

- Working full-time.....
- Working part-time.....
- Not working.....

If your partner is working, please go to question 15

13. Is your partner

- Looking after home/family.....
- Retired.....
- Long term sick/disabled.....
- Student.....
- None of the above.....

14. Has your partner *ever* worked?

- Yes..... *If Yes, please write how long it is since your partner last worked in months and years*
Years Months
- No..... **IF NO, please go straight to question 20**

15. Who is the main source of income for your family, you or your partner?

- I am the main source of income for our family.....
- My partner is the main source of income for our family.....
- Our income is equal.....

If YOU are the main source of income please go straight to question 20

Questions 16 -19 refer to your partner's current main job, or (if your partner is not working now) to his/her last main job.

16. Does (did) your partner work as an employer or is (was) s/he self-employed?

- Employee.....
- Self-employed with employees.....
- Self-employed/freelance without employees..

17. *For employees:* indicate below how many people work (worked) for your partner's employer at the place where s/he works (worked).

For self-employed: indicate below how many people your partner employs (employed). Go to question 19 when you have completed this question.

- 1-24
- 25 or more

18. Does (did) your partner supervise any other employees?
(A supervisor is responsible for overseeing the work of other employees on a day-to-day basis).

Yes..... No.....

19. Please tick one box to show which best describes the sort of work your partner does. (If your partner is not working now, please tick a box to show what s/he did in her/his last job).

PLEASE TICK ONE BOX ONLY

Modern professional occupations

such as: teacher – nurse – physiotherapist - social worker - welfare officer
– artist – musician - police officer (sergeant or above) – software designer 1

Clerical and intermediate occupations

such as: secretary - personal assistant - clerical worker - office clerk –
call centre agent - nursing auxiliary - nursery nurse 2

Senior managers or administrators

(usually responsible for planning, organising and co-ordinating work and
for finance) 3
such as: finance manager - chief executive

Technical and craft occupations

such as: motor mechanic – fitter – inspector – plumber – printer –
tool maker – electrician – gardener - train driver 4

Semi-routine manual and service occupations

such as: postal worker - machine operative - security guard – caretaker -
farm worker - catering assistant – receptionist - sales assistant 5

Routine manual and service occupations

such as: HGV driver - van driver – cleaner – porter – packer –
sewing machinist – messenger - labourer-waiter/waitress - bar staff 6

Middle or junior managers

such as: office manager - retail manager - bank manager –
restaurant manager - warehouse manager - publican 7

Traditional professional occupations

such as: accountant – solicitor - medical practitioner – scientist -
civil/mechanical engineer 8

20. How well would you say you are managing financially these days?

Would you say you are.... (Please ✓ a box)

Living comfortably

Doing alright.....

Just about getting by.....

Finding it quite difficult.....

Finding it very difficult

21. What is your ethnic background? (Please ✓ a box)

White.....

Mixed.....

Asian or Asian British.....

Black or Black British.....

Chinese.....

Other Ethnic Group.....

(Please describe below)

You have now reached the end of the questionnaire.

If there are any comments you would like to make please feel free to do so below.

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
Please return it to Suzanne Mukherjee, University of York,
in the pre-paid envelope provided



Appendix 26

**Study 4: Information sheet and questionnaire for children
(11-16 years)**



Invitation

Research on 'When Mum or Dad feels ill'

March 2002 (1)

Hello

My name is Suzanne and I am a student at the University of York. I have carried out lots of projects with children and young people to find out their views on things.

Why am I writing to you?

I would like to invite you to take part in the survey called 'When Mum or Dad feels ill'. The purpose of this survey is to find out what difference having a Mum or Dad who is sometimes ill makes to everyday life, and whether young people would like any help.

Why are you carrying out this project?

Last year I met 23 young people whose Mum or Dad is sometimes unwell - they have an illness which means they sometimes have an upset stomach and have to go to the toilet a lot (some young people call it Crohn's or ulcerative colitis or bowel disease). I talked with young people about what life is like for them when their Mum or Dad is ill. Now I would like to find out if other young people have similar experiences.

The information from the project will help people like doctors, nurses, and teachers know what kind of help families need.



How did you get my name?

If you get a leaflet from me, that's because your Mum/Dad has been contacted about the survey through his/her doctor and they have decided to pass this letter on to you.

What will I have to do?

If you want to take part, all you have to do is fill in the questionnaire and send it back to me in the envelope attached to it. You do not have to put a stamp on the envelope as the postage is already paid.



Will anyone else be told what I say?

No, everything you tell me is confidential. This means I will not let anyone see your questionnaire or tell them what you write. Your name, or any information that might identify

you or your family, will *not* be included in any reports written about the project. To help keep everything private, I have given you a code number and you do not have to put your name on the questionnaire.

What does the questionnaire ask about?

The questionnaire asks a bit about:

- What you think about your Mum/Dad's health
- Things you do to help your Mum/Dad
- Your free time
- School life
- Your family
- How things have been going for you recently
- Any help you would like



What will happen with the information?

Your response to the questionnaire will be put together with responses from other young people who take part. The results will then be analysed and written up in a report for the University of York. I will do two other things:

1. I will write a summary of the report for people who have taken part in the research - one for parents and another one for young people. *I will send your family a summary of the report.*
2. I will write articles and reports for people who might be able to offer help to families - people like nurses, doctors, and teachers.

Who else is taking part in the project?

I am writing to all the families of people who go to the same hospital clinic that your Mum or Dad attends. In every family, I am inviting parents and children aged between 11 and 16 to take part. I would like it if all the brothers and sisters in a family, aged between 11 and 16, would take part. After all, brothers and sisters can have different views on things!

Do I have to take part in the project?

No, you do not have to take part in the project. It's up to you to decide what you want to do.

If you decide to fill in the questionnaire, but find that you do not want to answer some questions, you can leave them out.



Thanks for reading this letter

Suzanne Mukherjee

If you would like to talk to me about the project,
telephone  01904 434118 between 9.00am and 5.30 pm Monday
to Friday.

If I am not there, please leave a message on the answer
phone.

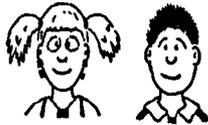
CODE							
------	--	--	--	--	--	--	--

This questionnaire is for young people aged 11-16 to fill in.
 If your child does not want or is unable to fill it in, please tick here and return the questionnaire in the envelope provided.

QUESTIONNAIRE FOR YOUNG PEOPLE

April 2002(2)

Research on 'When Mum or Dad feels ill'



This questionnaire asks you about:

- ❖ Your Mum/Dad's health
- ❖ Things you do to help your Mum/Dad
- ❖ Your free time
- ❖ School life
- ❖ Your family
- ❖ How things have been going for you recently
- ❖ Any help you would like

For most of the questions you just need to tick (✓) a box. It should take about 15 minutes to fill it in.

Your answers to this questionnaire are confidential. This means I will not let anyone see your questionnaire or tell them what you write. Your name, or any information that might identify you or your family, will not be included in reports about the project. To help keep everything private, I have given you a code number. You do not have to put your name on the questionnaire.

When you have filled in the questionnaire, please send it back to me in the envelope attached. You do not need to use a stamp - the postage is already paid.



Thanks for your help!
Suzanne

A BIT ABOUT YOU

What age are you?
(Please write below)

_____ years

Are you male or female?

(Please tick (✓) a box)

Female Male

YOUR MUM/DAD'S HEALTH

Before you took part in this project, how much had you talked to your Mum/Dad about their illness?

By illness, I mean the one that makes him/her have an upset stomach and have to go to the toilet a lot.

(Please tick (✓) one box)

- Never talked about it
 Talked a little
 Talked a lot

In your opinion, how serious is your Mum/Dad's illness?

By illness, I mean the one that makes him/her have an upset stomach and have to go to the toilet a lot.

(Please tick (✓) one box)

- Not at all serious
 A little bit serious
 Quite serious
 Very serious

THINGS YOU DO TO HELP MUM OR DAD



In the box below are some of the things that young people have said they do to help their Mum or Dad. Please tell me whether these are things you have done during the past month by ticking (✓) the boxes that apply to you.

	Never did this	Sometimes did this	Often did this	Did this all the time
Looked after a brother or sister	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stayed at home to make sure Mum/Dad was okay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made drinks or snacks for Mum/Dad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped Mum or Dad prepare meals - e.g. set the table, help chop up vegetables etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cooked lunch or dinner for members of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

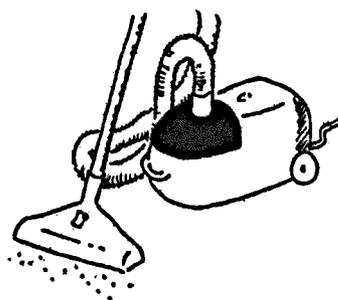
	Never did this	Sometimes did this	Often did this	Did this all the time
Washed and/or dried dishes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Washed and/or ironed clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kept my room tidy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tidied the rest of the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Went shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If there is anything else you did to help during the last month, please describe it in the box below *and* tick (✓) how often you did it.

Other things I did to help Mum/Dad	Never Did this	Sometimes did this	Often did this	Did this all the time
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About how much time do you usually spend in a week doing chores around the house, such as washing up, tidying your bedroom and cleaning?

- None or almost none
- Under 1 hour
- 1-2 hours
- 3-5 hours
- 6 hours or more



Young people vary in how much they do to help around the house. How much do you think you do compared to other people your age?

- Less than other people
- The same as other people
- More than other people



YOUR FREE TIME

This section asks about how much time you get to spend with your friends and other people your age.

How much time do you spend together with friends?

(Please tick (✓) one box)

- All of your free time
- Some of your spare time
- A little of your spare time
- No time

How often do friends come to your house?

(Please tick (✓) one box)

- All of your free time
- Some of your spare time
- A little of your spare time
- No time

How often do you go to their house?

(Please tick (✓) one box)

- All of your free time
- Some of your spare time
- A little of your spare time
- No time

Over the past 12 months have you belonged to any teams, clubs or groups with an adult in charge? For example, guides, scouts, school clubs.

- Yes
- No



SCHOOL LIFE

This section asks about how things have been going for you at school over the last year.

Have you had to miss any school days over the last year because your parent has been unwell? *By parent, I mean the one who has an upset stomach and has to go to the toilet a lot.*

- No
- Yes

If YES, how many days have you missed in the last year? (Please ✓ one box)

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| 1-2 days | 2-5 days | 6-10 days | More than 10 days |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

YOUR FAMILY



This section asks about how you get along with people in your family.

How often do you talk to your Mum about things that matter to you? Is it...

(Please tick (✓) a box below)

- Most days
- More than once a week
- Less than once a week
- Hardly ever
- Don't have a Mum/or Mum does not live at home

How often do you talk to your Dad about things that matter to you? Is it...

(Please tick (✓) a box below)

- Most days
- More than once a week
- Less than once a week
- Hardly ever
- Don't have a Dad/or Dad does not live at home

Most children have occasional quarrels with their parents. How often do you quarrel with your Mum?

(Please tick (✓) a box below)

- Most days
- More than once a week
- Less than once a week
- Hardly ever
- Don't have a Mum/or Mum does not live at home

How often do you quarrel with your Dad?

(Please tick (✓) a box below)

- Most days
- More than once a week
- Less than once a week
- Hardly ever
- Don't have a Mum/or Mum does not live at home

HOW THINGS HAVE BEEN GOING FOR YOU RECENTLY

The questions on the next two pages are about what you see as your strengths and difficulties.

For each item below, please mark the box for *Not True*, *Somewhat True* or *Certainly True*. It would help me if you answered all items as best you can even if you are not absolutely certain or the item seems a bit daft! Please give your answers in the basis of how things have been going for you over the last six months.

	Not true	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others (food, games, pens etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own, I generally play on my own or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset, or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents/teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I am doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall, do you think that you have difficulties in one or more of the following areas:
emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- Severe difficulties
↑	↑	↑	↑

If you have answered 'No', please go to the questions on the next page about 'HELP YOU WOULD LIKE'

If you have answered 'Yes', please answer the following questions about these difficulties:

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
↑	↑	↑	↑

- Do these difficulties upset or distress you?

Not at All	Only a little	Quite a lot	A great deal
↑	↑	↑	↑

- Do the difficulties interfere with your everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
Home Life	↑	↑	↑	↑
Friendships	↑	↑	↑	↑
Classroom Learning	↑	↑	↑	↑
Leisure Activities	↑	↑	↑	↑

- Do the difficulties make it harder for those around you (family, friends, teachers etc.)?

Not at all	Only a little	Quite a lot	A great deal
↑	↑	↑	↑

HELP YOU WOULD LIKE

Listed below are four suggestions young people have made about help they would like. I would like to know if *you* need these things. (*Unfortunately I cannot get you help, I can only write a report about the help young people would like and hope others take notice*).

For each statement please tick (✓) the box that best describes your situation.

Suggestion 1: I want information and advice about Mum/Dad's health

(Please tick one of the boxes below)

- I do *not* want any information and advice
- I have got enough information and advice
- I would like more information and advice

Suggestion 2: I want someone to talk to about how I feel about Mum/Dad's health.

(Please tick one of the boxes below)

- I do *not* want someone to talk to
- I already have someone to talk to
- I would like someone to talk to

Suggestion 3: I would like to meet other young people whose Mum or Dad is sometimes unwell.

(Please tick one of the boxes below)

- I do *not* want to meet other young people whose Mum/Dad is unwell
- I already know another young person whose Mum/Dad is unwell
- I would like to meet other young people whose Mum/Dad is unwell

Suggestion 4: I would like someone to help my family with things around the house like cleaning and cooking.

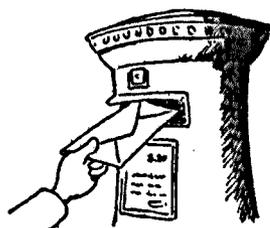
(Please tick one of the boxes below)

- I do *not* want someone to help my family around the house
- We already have someone to help us around the house
- I would like someone to help us with things around the house

You have reached the end of the questionnaire!

If there is any other help you would like, or anything else you want to tell me, please write or draw in the box below.

Please send the questionnaire back to me in the envelope attached.



😊 Thanks for taking part in the survey

Suzanne Mukherjee

Appendix 27

Study 3: Article printed in NACC newsletter

SURVEY OF PARENTS

Do you have inflammatory bowel disease AND have children living at home aged 16 years or younger?

If the answer is **YES**, I would like to invite you to take part in a survey. The aim is to find out:

- ❖ how IBD affects family life
- ❖ whether there is a need to improve the help offered to families

The research will provide useful information for NACC and staff in gastroenterology clinics about how best to support families.

Taking part simply involves completing and returning a postal questionnaire.

Even if you feel having IBD has made little difference to your family, ! would still like to hear from you.

For further information please contact:

Suzanne Mukherjee
Department of Health Sciences
University of York, Genesis 6
Heslington
York, YO10 5DQ
Tel: 01904 434118
E mail: Skmw1@york.ac.uk

Appendix 28

**Study 3: Tests on normality of distribution of ordinal and interval
level variables for survey of parents**

Table 1: Tests on normality of distributions for survey of parents

Scale	Skewness	Standard error	Kurtosis	Standard error	Outliers
Health					
Reduced SIBDQ	-0.26	0.19	-.050	0.37	no
Duration of symptoms	0.76	0.18	.039	0.36	n=2
Time since diagnosis	-0.52	0.18	-0.89	0.36	no
Frequency of outpatient appointments in past year	0.93	0.19	0.71	0.37	n=5
Frequency of hospitalisations for IBD during life	0.40	0.18	-1.14 *	0.36	no
Frequency of surgery for IBD during life	1.03*	0.18	-0.06	0.36	n=3
General perception of health	-0.15	0.18	-0.21	0.37	n=3
Socio-demographics					
Age of youngest child	0.50	0.18	-1.01*	0.36	no
Age of children in 4-16 year sample for which SDQs were completed	0.228	0.166	-1.113	0.331	no
Number of children under 16 years living at home	0.71	0.18	0.11	0.36	n=3
Perception of financial situation	0.27	0.18	-0.67	0.36	n=11
Family socio-economic classification	0.797	0.184	-1.02*	.365	n0
Age of parent	0.58	0.18	1.38*	0.36	n=3
Parent's responsibility for domestic labour	-0.74	0.19	-0.79	0.39	no
Difficulties with parenting					
Infant PTI score	0.78	0.58	-0.92	1.12	no
Child PTI score	1.01	0.22	0.63	0.45	n=7
Adolescent PTI score	0.95	0.31	0.56	0.61	n=1
Average standardised PTI score	1.09*	0.20	0.90	0.39	n=7
Family social support					
HADS anxiety score	0.27	0.18	-0.53	0.36	no
HADS depression score	0.60	0.18	0.37	0.36	n=3
Parent's SDQ data					
Total difficulties score	0.55	0.17	-0.30	0.34	n=1
Emotional symptoms	0.62	0.17	-0.44	0.33	no
Conduct problems	0.99*	0.17	0.99	0.33	n=9
Hyperactivity	0.48	0.17	-0.61	0.33	no
Peer problems	0.93	0.17	0.19	0.34	no
Prosocial Behaviour	-0.84	0.17	0.31	0.33	n=1
Impact score	2.45*	0.17	6.0*	0.33	n= 27

Table 2: Distribution of parents' SDQ data for 5-15 year olds

Scale	Skewness	Standard error	Kurtosis	Standard error	Outliers
Total difficulties	0.56	.18	-0.34	.36	n= 1
Emotional	0.64	.18	-0.44	.35	no
Conduct	0.97	.18	0.95	.35	n= 1
Hyperactivity	0.44	.18	-0.74	.35	no
Peer	1.00	.18	0.36	.36	n= 1
Prosocial	-0.86	.18	0.36	.35	n=1
Impact	2.38	.18	5.63	.35	scores>3 n=18

Appendix 29

Study 3: Effect of transformations- survey of parents

Successful transformations

Log transformation improved the distribution of the following variables:

- average standardised PTI score (skewness=0.86, standard error =0.20; kurtosis=0.32;standard error 0.39)
- how many years the respondent had been experiencing symptoms of IBD (skewness=0.18, standard error =0.18; kurtosis=-.89; standard error 0.36)

Unsuccessful transformations

Variables used in the survey of parents, not improved by transformation, and therefore treated as ordinal level data were:

- length of diagnosis
- frequency of hospitalisation
- frequency of surgery
- frequency of outpatient appointments
- age of youngest child in years
- number of children age 16 and under living at home
- division of household labour
- socio-economic status
- infant PTI scale score
- child PTI scale score
- adolescent PTI scale score
- parent-rated SDQ conduct problems
- parent-report SDQ peer problems
- parent-report SDQ prosocial behaviour
- parent-report SDQ impact score.

Appendix 30

**Study 3: Testing for differences between clinic and NACC samples
in parent survey**

**Table1: NACC versus clinic sample comparison for the parent's survey-
Analysis of categorical variables**

Variable	Chi- square	Df	Sig.
Parent's sex	1.131	1	.288
Parent's work situation	4.372	2	.112
Whether parent is living with a partner	1.949	1	.163
Partner's work situation	0.034	2	.983
Parent's diagnosis	4.709	1	.030
Whether parent has another long term illness/health problem/disability	0.107	1	.743
Whether parent's partner has long term illness/health problem/ disability	6.171	1	.013
Whether child has a long term illness, health problem or disability	0.207	1	.649
Whether parent has stayed overnight in hospital within the last year	0.940	1	.332
Whether parent had surgery within the last year	0.152	1	.697
Whether parent was prescribed medication in the last year	0.520	1	.820
Whether parent was prescribed steroids within the last year	0.949	1	.330
Whether parent was prescribed azathioprine within the last year	0.119	1	.731
Support Needs			
1. <i>Advice on stress management</i>	0.587	1	.444
2. <i>Access to disabled parking to make it easier to get to toilets quickly</i>	2.862	1	.091
3. <i>Information and advice on the effects of IBD on family life</i>	0.959	1	.327
4. <i>More than one toilet in our house</i>	0.316	1	.574
5. <i>A booklet which explains IBD to my child</i>	2.392	1	.122
6. <i>Advice on explaining IBD to my child</i>	1.284	1	.257
7. <i>An opportunity to talk to a counsellor about coping with IBD</i>	7.175	1	.007
8. <i>An opportunity to talk to other parents with IBD</i>	5.260	1	.022
9. <i>Someone to look after my child when I have hospital appointments</i>	4.865	1	.027
10. <i>Financial support to assist with prescriptions</i>	0.801	1	.371
11. <i>My partner needs information and advice on IBD</i>	7.111	1	.008
12. <i>Time to recover from treatment before being sent home from hospital</i>	3.504	1	.061
13. <i>Help with housework</i>	0.288	1	.591
14. <i>Someone to look after my child when I am in hospital overnight</i>	0.139	1	.710
15. <i>Help getting my child to and from school</i>	3.022	1	.082
16. <i>My partner needs someone to talk to about me having IBD</i>	5.440	1	.020
17. <i>Help with shopping</i>	1.229	1	.268
18. <i>My family needs an opportunity to meet other families in a similar situation</i>	6.255	1	.012
19. <i>Help contacting family in times of a medical emergency</i>	0.001	1	.982

Table1: NACC versus clinic sample comparison for the parent's survey- Analysis of categorical variables			
Variable	Chi- square	Df	Sig.
20. <i>Help preparing meals</i>	0.128	1	.720
21. <i>Information & advice on ileostomies</i>	2.930	1	.087
22. <i>Information & advice on returning home after surgery</i>	0.177	1	.674
23. <i>Information and advice on the effects of IBD on pregnancy</i>	0.359	1	.549
24. <i>Home treatment for bowel rest & tube feeding so do not have to go into hospital</i>	2.241	1	.134

Table 2: Proportion of respondents with support needs split according to whether recruited from NACC or hospital clinic	
Type of help needed	% support needing split by where recruited from
An opportunity to talk to a counsellor	NACC 60.5 Hospital 38.0
An opportunity to talk to other parents with IBD	NACC 55.0 Hospital 35.4
Someone to look after my child when I have hospital appointments	NACC 50.4 Hospital 32.0
Information and advice on IBD for partner	NACC 46.0 Hospital 23.4
Someone for partner to talk to about respondent having IBD	NACC 37.5 Hospital 18.8
An opportunity for the family to meet other families in a similar situation	NACC 14.3 Hospital 33.3

Table 3: NACC versus clinic sample comparison for the parent's survey - analysis of Interval level variables				
Variable	t	df	Sig.	95% confidence interval
Parent's age	-1.552	176	.27	-3.694 to 0.4654
SIBDQ	-1.134	169	.258	-0.658 to 0.177
General perception of health	-0.475	172	.635	-0.375 to 0.229
Family social support	0.282	157	.779	-3.172 to 4.228
HADS anxiety score	-.124	174	.902	-1.514 to 1.336
HADS depression score	.93	176	.355	-0.706 to 1.956

Table 4: NACC versus clinic sample comparison for the parent's survey - analysis of ordinal level variables

Variable	Z	Sig.
Number of children under 16 years living at home	-1.391	.164
Age of youngest child	-0.182	.856
Household socio-economic status	-0.435	.664
Financial situation	-0.108	.914
Parent's highest education qualification	-0.554	.579
Division of household labour	-1.300	.193
Number of years had symptoms	-0.276	.783
Length of diagnosis	-0.616	.538
Frequency of outpatient clinics	-3.288	.001
Frequency of overnight stays in hospital	-1.859	.063
Frequency of surgery for IBD	-0.501	.616
Infant PTI scale score	-0.869	.385
Child PTI scale score	-2.413	.016
Adolescent PTI scale score	-0.649	.516
Average standardised PTI score	-1.932	.053
Parent-report SDQ total difficulties score	-0.273	.783
Parent-report SDQ emotional symptoms	-0.838	.402
Parent-report SDQ conduct problems	-0.470	.638
Parent-report SDQ hyperactivity	-0.945	.344
Parent-report SDQ peer problems	-0.064	.949
Parent-report SDQ prosocial behaviour	-0.597	.550
Parent-report SDQ impact score	-1.949	.051

Appendix 31

**Study 3: Chi-square analysis of division of household tasks
according to sex**

Table 1: Chi-square analysis of division of household tasks according to sex						
Task	Response			Chi-square	Df	Significance
	Mostly self	Mostly spouse/ partner	Shared			
<i>Grocery shopping</i>						
Females (%)	62.5	11.7	25.8	28.177	2	<0.001
Males (%)	15.6	46.9	37.5			
<i>Cooking</i>						
Females (%)	73.0	5.7	21.3	62.084	2	<0.001
Males (%)	12.5	62.5	25.0			
<i>Cleaning/ hoovering</i>						
Females (%)	70.9	6.8	22.2	69.520	2	<0.001
Males (%)	6.3	71.9	21.9			
<i>Washing & Ironing</i>						
Females (%)	81.7	1.7	16.7	114.785	2	<0.001
Males (%)	3.1	84.4	12.5			
<i>Care of children under 12 years</i>						
Females (%)	74.5	1.8	23.6	69.602	2	<0.001
Males (%)	3.3	50	46.7			

Appendix 32

**Study 3: Testing for associations between parents' support needs
and independent variables**

Table 1 : Testing for association between help needed and parent's diagnosis

Type of help needed	Chi-Square	Df	Sig.
1. Advice on stress management	0.155	1	.693
2. Access to disabled parking to make it easier to get to toilets quickly	0.263	1	.608
3. Information and advice on the effects of IBD on family life	0.119	1	.730
4. More than one toilet in our house	0.926	1	.336
5. A booklet which explains IBD to my child	1.307	1	.253
6. Advice on explaining IBD to my child	4.114	1	.043
7. An opportunity to talk to a counsellor about coping with IBD	0.277	1	.599
8. An opportunity to talk to other parents with IBD	0.004	1	.953
9. Someone to look after my child when I have hospital appointments	2.0666	1	.151
10. Financial support to assist with prescriptions	1.250	1	.264
11. My partner needs information and advice on IBD	0.330	1	.566
12. Time to recover from treatment before being sent home from hospital	8.407	1	.004
13. Help with housework	1.533	1	.216
14. Someone to look after my child when I am in hospital overnight	13.865	1	<.001
15. Help getting my child to and from school	1.156	1	.282
16. My partner needs someone to talk to about me having IBD	2.516	1	.113
17. Help with shopping	0.001	1	.973
18. My family needs an opportunity to meet other families in a similar situation	0.129	1	.719
19. Help contacting family in times of a medical emergency	5.669	1	.017
20. Help preparing meals	0.000	1	.983
21. Information & advice on ileostomies	0.429	1	.512
22. Information & advice on returning home after surgery	9.671	1	.002
23. Information and advice on the effects of IBD on pregnancy	0.019	1	.892
24. Home treatment for bowel rest & tube feeding so do not have to go into hospital	4.257	1	.039

Table 2 : Testing for association between help needed and parent's sex

Type of help needed	Chi-Square	Df	Sig.
1. Advice on stress management	3.709	1	.054
2. Access to disabled parking to make it easier to get to toilets quickly	8.018	1	.005
3. Information and advice on the effects of IBD on family life	0.560	1	.454
4. More than one toilet in our house	1.368	1	.242
5. A booklet which explains IBD to my child	8.267	1	.004
6. Advice on explaining IBD to my child	8.599	1	.003
7. An opportunity to talk to a counsellor about coping with IBD	4.174	1	.041
8. An opportunity to talk to other parents with IBD	3.395	1	.065
9. Someone to look after my child when I have hospital appointments	15.776	1	<.001
10. Financial support to assist with prescriptions	2.062	1	.151
11. My partner needs information and advice on IBD	0.026	1	.871
12. Time to recover from treatment before being sent home from hospital	6.223	1	.013
13. Help with housework	6.009	1	.014
14. Someone to look after my child when I am in hospital overnight	5.100	1	.024
15. Help getting my child to and from school	3.013	1	.083
16. My partner needs someone to talk to about me having IBD	0.115	1	.734
17. Help with shopping	7.455	1	.006
18. My family needs an opportunity to meet other families in a similar situation	0.373	1	.541
19. Help contacting family in times of a medical emergency	3.220	1	.073
20. Help preparing meals	3.333	1	.068
21. Information & advice on ileostomies	0.674	1	.412
22. Information & advice on returning home after surgery	0.744	1	.388
23. Information and advice on the effects of IBD on pregnancy	9.855	1	.002
24. Home treatment for bowel rest & tube feeding so do not have to go into hospital			Not calculated

**Table 3 : Testing for association between help needed and age group
of youngest child**

Type of help needed	Chi-Square	Df	Sig.
1. Advice on stress management	0.167	2	.920
2. Access to disabled parking to make it easier to get to toilets quickly	0.114	2	.945
3. Information and advice on the effects of IBD on family life	6.145	2	.046
4. More than one toilet in our house	2.565	2	.277
5. A booklet which explains IBD to my child	0.914	2	.633
6. Advice on explaining IBD to my child	0.452	2	.798
7. An opportunity to talk to a counsellor about coping with IBD	1.052	2	.591
8. An opportunity to talk to other parents with IBD	7.607	2	.022
9. Someone to look after my child when I have hospital appointments	12.104	2	.002
10. Financial support to assist with prescriptions	2.544	2	.280
11. My partner needs information and advice on IBD	2.066	2	.356
12. Time to recover from treatment before being sent home from hospital	7.980	2	.018
13. Help with housework	1.948	2	.378
14. Someone to look after my child when I am in hospital overnight	2.043	2	.360
15. Help getting my child to and from school	7.768	2	.021
16. My partner needs someone to talk to about me having IBD	0.447	2	.800
17. Help with shopping	1.265	2	.531
18. My family needs an opportunity to meet other families in a similar situation	9.022	2	.011
19. Help contacting family in times of a medical emergency	0.514	2	.773
20. Help preparing meals	1.808	2	.405
21. Information & advice on ileostomies	5.288	2	.071
22. Information & advice on returning home after surgery	6.584	2	.037
23. Information and advice on the effects of IBD on pregnancy	14.186	2	.001
24. Home treatment for bowel rest & tube feeding so do not have to go into hospital	1.891	2	.388

Appendix 33

**Study 4: Tests on normality of distribution of ordinal and interval
level variables- survey of children**

Table 1: Tests on normality of distributions for survey of children

Scale	Skewness	Standard error	kurtosis	Standard error	Outliers
Parent's health					
Reduced SIBDQ	-0.202	0.29	-0.54	0.57	no
Duration of symptoms	0.49	0.28	-0.53	0.56	no
Time since diagnosis	-0.89	0.28	-0.27	0.55	no
Frequency of outpatient appointments in past year	0.64	0.28	-0.49	0.56	no
Number of hospitalisations for IBD during life	0.24	0.28	-1.41*	0.55	no
Number of times had surgery for IBD during life	0.98*	0.28	-0.42	0.56	no
General perception of health	-0.15	0.28	-0.82	0.56	n= 1
Socio-demographics					
Perception of financial situation	0.32	0.28	-0.66	0.55	n= 4
Household socio-economic classification	0.88	0.28	-0.94	0.55	no
Age of child	0.189	0.279	-1.249	0.552	no
Age of parent	0.70	0.28	0.07	0.55	no
Number of children under 16 years living at home	0.57	0.28	-0.35	0.55	no
Parent's responsibility for domestic labour	-0.72	0.30	-0.75	0.59	no
Average standardised PTI score	1.07*	0.30	0.37	0.60	no
Adolescent PTI score	1.024	0.297	0.369	0.586	n=3
Involvement in helping parent	0.58	0.29	0.67	0.58	n=1
Social support	0.59	0.29	1.16	0.58	n=6
HADS anxiety score	0.56	0.28	-0.13	0.55	n=1
HADS depression score	0.63	0.28	0.51	0.55	n=1
Self-report SDQ data					
Total difficulties score	0.38	0.29	0.18	0.57	n=1
Emotional symptoms	0.30	0.29	-0.43	0.57	no
Conduct problems	1.14*	0.28	0.91	0.56	n=5
Hyperactivity	0.47	0.28	0.32	0.55	n=2
Peer problems	1.12*	0.28	0.83	0.56	n=1
Prosocial Behaviour	-0.22	0.28	0.85	0.55	no
Impact score	2.85*	0.28	7.86*	0.55	n=13
Total social activity	-0.79	0.28	0.65	0.55	n= 4

Appendix 34

Study 4: Effect of transformations- survey of children

Successful transformations

Log transformation improved the distribution of the following variables:

- self-report SDQ conduct score (skewness =0.83, standard error =0.28; kurtosis=0.19;standard error 0.56)
- adolescent PTI scores (skewness=-0.96, standard error = 0.28; kurtosis=1.33;standard error 0.56).

Unsuccessful transformations

Variables used in the survey of young people, not improved by transformation, and therefore treated as ordinal level data were:

- young person's social activity score.
- self-report SDQ peer problems
- self-report SDQ prosocial behaviour
- self-report SDQ impact score
- number of years the parent had been experiencing symptoms of IBD
- length of diagnosis
- frequency of surgery
- frequency of overnight stays in hospital
- frequency of attending outpatient clinic
- general perception of health
- division of household labour
- number of children under the age of 16 living at home
- family socio-economic classification

Appendix 35

**Study 4: Testing for differences between clinic and NACC samples
in the survey of children**

**Table 1: NACC versus clinic sample comparison for the children's survey-
analysis of categorical variables**

Variable	χ^2	Df	Sig.
Parent data			
Parent's sex			Not calculated
Parent's employment status	.246	2	.884
Parent's highest educational qualification			Not calculated
Ethnic group			Not calculated
Whether parent is living with a partner			Not calculated
Partner's employment situation			Not calculated
Parent's diagnosis (whether has UC or CD)	3.375	1	.066
Time since diagnosis			Not calculated
Whether parent has long term illness/health problem/ disability other than IBD	3.944	1	.047
Whether other parent has a long term illness/health problem/disability			Not calculated
Whether parent has stayed overnight in hospital within the last year	3.44	1	.063
Whether parent had surgery within the last year			Not calculated
Whether parent was prescribed medication in the last year			Not calculated
Whether parent was prescribed steroids within the last year	1.069	1	.301
Whether parent was prescribed azathioprine within the last year	1.717	1	.189
Whether parent has an ileostomy			Not calculated
Frequency of attending outpatient clinic	10.566	3	.014
Child data			
Child's sex	0.967	1	.326
Whether child has a long term illness/health problem/disability	3.944	1	.047
How much they had talked to parent about IBD	6.95	1	.326
Perception of seriousness of parent's illness	.0005	1	.946
Perception of involvement in housework	0.877	2	
Amount of time spent per week on household chores	3.021	2	.221
Missed school because of parent's illness			Not calculated
Whether child had belonged to any teams, clubs or other groups over the past 12 months	4.409	1	.036
How much time is spent with friends			Not calculated
How often friends came to the young person's house	0.413	1	.521
How often child went to a friend's house	0.416	1	.519
Frequency of talking to Mum about things that are important to them	1.005	1	.316
Frequency of talking to Dad about things that are important to them	0.034	1	.853
Frequency of quarreling with Mum	2.234	1	.135
Frequency of quarreling with Dad	0.684	1	.408
I want information and advice about Mum/Dad's health			Not calculated
I would like someone to help around the house with things like cooking and cleaning	0.005	1	.945
I would like to meet other young people whose Mum or Dad is sometimes unwell	0.061	1	.804
I want someone to talk to about how I feel about Mum/Dad's health	1.406	1	.236

NB. Where 'not calculated' this is due to low expected cell counts

**Table 2: NACC versus clinic sample comparison for the children's survey-
analysis of interval level variables**

Variable	t	Df	Sig.	95% confidence interval for the difference
Parent variable				
Parent's age	-2.132	56.26	.037	-4.9460 to -0.1548
SIBDQ	0.249	66	.804	-0.5862 to 0.7535
HADS anxiety score	.897	72	.373	-2.92 to 1.11

**Table 3: NACC versus clinic sample comparison for the children's survey-
analysis of ordinal level variables**

Variable	Z	Sig.
Parent variables		
Number of children under 16 years living at home	-1.563	.118
General perception of health	-1.124	.261
Household socio-economic status	-.0520	.603
Financial situation	-.0870	.384
Parent's highest education qualification	-1.755	.079
Division of household labour	-.0050	.960
Length of diagnosis	-.0263	.793
Length of symptoms	-.0955	.339
Frequency of attending outpatient clinics	-2.528	.011
Frequency of overnight stays in hospital	-1.760	.078
Frequency of surgery for IBD	-.0392	.695
Family social support	-1.352	.260
Adolescent PTI	-1.126	.260
HADS depression score	-.0981	.327
Child variables		
Child's age	-0.655	.512
Self-report SDQ total difficulties score	1.2409	.159
Self-report SDQ emotional symptoms	-1.651	.099
Self-report SDQ conduct problems	-1.068	.286
Self-report SDQ hyperactivity	-0.661	.509
Self-report SDQ peer problems	-0.074	.941
Self-report SDQ prosocial behaviour	-1.005	.315
Self-report SDQ impact score	1.384	.166

Appendix 36

**Study 4: Testing for associations between support needs and
independent variables**

Table 1 : Testing for association between help needed and child's sex

Type of help needed	Chi-Square	Df	Sig.
1. Information and advice about Mum/Dad's health	0.175	1	.676
2. Someone to help with things around the house like cooking and cleaning	0.690	1	.406
3. To meet other young people whose Mum or Dad is unwell	0.021	1	.884
4. Someone to talk to about how I feel about Mum/Dad's health	0.676	1	.411

Table 2 : Testing for association between help needed and parent's sex

Type of help needed	Chi-Square	Df	Sig.
1. Information and advice about Mum/Dad's health			Not calculated
2. Someone to help with things around the house like cooking and cleaning			Not calculated
3. To meet other young people whose Mum or Dad is unwell			Not calculated
4. Someone to talk to about how I feel about Mum/Dad's health	2.526	1	.112

Not calculated – due to low expected cell counts

Table 3 : Testing for association between help needed and parent's diagnosis

Type of help needed	Chi-Square	Df	Sig.
1. Information and advice about Mum/Dad's health	0.918	1	.338
2. Someone to help with things around the house like cooking and cleaning	0.571	1	.450
3. To meet other young people whose Mum or Dad is unwell	3.897	1	.048
4. Someone to talk to about how I feel about Mum/Dad's health	1.248	1	.264

Appendix 37

Bivariate analysis of HADS data according to independent variables

Independent variable	F	Df	Significance
Respondent's work situation	6.26	2,173	.002
Presence of an ileostomy	0.14	2,172	.868
Partner's work situation	0.47	2,150	.623

Independent variable	t	Df	Significance
Diagnosis (CD or UC)	1.28	68	.201

Independent variable	F	Df	Significance
Respondent's work situation	11.09	2,175	<.001
Presence of an ileostomy	0.86	2,174	.424
Partner's work situation	0.07	2,152	.932

Independent variable	t	Df	Significance
Diagnosis (UC or CD)	2.125	167	.035

Table 5: Correlation matrix for interval level health variables and anxiety

Correlations

		Total HADS anxiety score	SIBDQ minus psychological distress	Log of length of symptoms add 10	Have you stayed overnight in hospital in last year	Surgery in the last year	Prescribed regular medication in last year	Prescribed steroids in last year	Prescribed azathioprine in last year	Any other long term illnesses	General perception of health
Total HADS anxiety score	Pearson Correlation	1	-.478**	.097	-.014	-.112	.158*	.045	-.050	.261**	.423**
	Sig. (2-tailed)	.	.000	.204	.850	.140	.037	.554	.514	.000	.000
	N	176	169	174	175	174	174	175	174	175	173
SIBDQ minus psychological distress	Pearson Correlation	-.478**	1	-.143	-.130	-.143	-.252**	-.255**	-.072	-.414**	-.658**
	Sig. (2-tailed)	.000	.	.063	.091	.063	.001	.001	.355	.000	.000
	N	169	171	170	170	169	169	170	169	170	168
Log of length of symptoms add 10	Pearson Correlation	.097	-.143	1	-.042	.061	-.053	-.152*	-.057	.099	.105
	Sig. (2-tailed)	.204	.063	.	.578	.421	.489	.045	.456	.192	.168
	N	174	170	176	176	175	175	176	175	176	173
Have you stayed overnight in hospital in last year	Pearson Correlation	-.014	-.130	-.042	1	.528**	-.046	.120	.017	.069	.061
	Sig. (2-tailed)	.850	.091	.578	.	.000	.545	.112	.827	.360	.424
	N	175	170	176	177	176	176	177	176	177	174
Surgery in the last year	Pearson Correlation	-.112	-.143	.061	.528**	1	.020	.117	-.080	.061	.008
	Sig. (2-tailed)	.140	.063	.421	.000	.	.789	.122	.291	.422	.912
	N	174	169	175	176	176	175	176	175	176	173
Prescribed regular medication in last year	Pearson Correlation	.158*	-.252**	-.053	-.046	.020	1	.299**	.280**	.153*	.201**
	Sig. (2-tailed)	.037	.001	.489	.545	.789	.	.000	.000	.042	.008
	N	174	169	175	176	175	176	176	175	176	173
Prescribed steroids in last year	Pearson Correlation	.045	-.255**	-.152*	.120	.117	.299**	1	.169*	.140	.166*
	Sig. (2-tailed)	.554	.001	.045	.112	.122	.000	.	.025	.063	.029
	N	175	170	176	177	176	176	177	176	177	174
Prescribed azathioprine in last year	Pearson Correlation	-.050	-.072	-.057	.017	-.080	.280**	.169*	1	-.025	.076
	Sig. (2-tailed)	.514	.355	.456	.827	.291	.000	.025	.	.746	.319
	N	174	169	175	176	175	175	176	176	176	173
Any other long term illnesses	Pearson Correlation	.261**	-.414**	.099	.069	.061	.153*	.140	-.025	1	.493**
	Sig. (2-tailed)	.000	.000	.192	.360	.422	.042	.063	.746	.	.000
	N	175	170	176	177	176	176	177	176	177	174
General perception of health	Pearson Correlation	.423**	-.658**	.105	.061	.008	.201**	.166*	.076	.493**	1
	Sig. (2-tailed)	.000	.000	.168	.424	.912	.008	.029	.319	.000	.
	N	173	168	173	174	173	173	174	173	174	174

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 6 : Correlation matrix for interval level non-health variables and anxiety

Correlations

		Total HADS anxiety score	Parent sex	Currently living with a partner	How are you managing financially	Parent age in years	Does partner have any illness etc	Average PTI score - log tranformation	Total family support scale score (excluding others)
Total HADS anxiety score	Pearson Correlation	1	-.149*	-.175*	.278**	.032	-.050	.365**	-.198*
	Sig. (2-tailed)	.	.049	.020	.000	.674	.541	.000	.013
	N	176	176	176	175	176	154	150	157
Parent sex	Pearson Correlation	-.149*	1	.093	-.047	.179*	.021	-.080	.084
	Sig. (2-tailed)	.049	.	.215	.537	.017	.794	.330	.290
	N	176	178	178	177	178	156	152	159
Currently living with a partner	Pearson Correlation	-.175*	.093	1	-.168*	.027	^a	-.195*	.198*
	Sig. (2-tailed)	.020	.215	.	.025	.723	.	.016	.013
	N	176	178	178	177	178	156	152	159
How are you managing financially	Pearson Correlation	.278**	-.047	-.168*	1	-.097	.114	.288**	-.108
	Sig. (2-tailed)	.000	.537	.025	.	.197	.158	.000	.177
	N	175	177	177	177	177	155	152	159
Parent age in years	Pearson Correlation	.032	.179*	.027	-.097	1	.108	.039	-.193*
	Sig. (2-tailed)	.674	.017	.723	.197	.	.182	.636	.015
	N	176	178	178	177	178	156	152	159
Does partner have any illness etc	Pearson Correlation	-.050	.021	^a	.114	.108	1	.194*	-.058
	Sig. (2-tailed)	.541	.794	.	.158	.182	.	.023	.492
	N	154	156	156	155	156	156	138	142
Average PTI score - log tranformation	Pearson Correlation	.365**	-.080	-.195*	.288**	.039	.194*	1	-.184*
	Sig. (2-tailed)	.000	.330	.016	.000	.636	.023	.	.030
	N	150	152	152	152	152	138	152	139
Total family support scale score (excluding others)	Pearson Correlation	-.198*	.084	.198*	-.108	-.193*	-.058	-.184*	1
	Sig. (2-tailed)	.013	.290	.013	.177	.015	.492	.030	.
	N	157	159	159	159	159	142	139	159

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

a. Cannot be computed because at least one of the variables is constant.

Table 7: Correlation matrix for ordinal level variables and anxiety

Correlations

			Total HADS anxiety score	Parent qualification 4 categories	Family socio-economic classification	Frequency of surgery	Length of diagnosis	Total number of overnight stays in hospital	Age of youngest child in years	Number of children under 16 years living at home	Composite score of division of household labour
Spearman's rho	Total HADS anxiety score	Correlation Coefficient	1.000	.202**	.153*	.038	-.020	.088	.041	-.041	.113
		Sig. (2-tailed)	.	.008	.044	.620	.790	.244	.592	.591	.167
		N	176	174	173	173	176	175	176	176	152
	Parent qualification 4 categories	Correlation Coefficient	.202**	1.000	.430**	.102	-.061	.071	.141	-.032	.222**
		Sig. (2-tailed)	.008	.	.000	.180	.422	.352	.063	.674	.006
		N	174	176	173	173	176	175	176	176	152
	Family socio-economic classification	Correlation Coefficient	.153*	.430**	1.000	-.151*	-.221**	-.081	-.047	-.001	.256**
		Sig. (2-tailed)	.044	.000	.	.048	.003	.289	.535	.985	.001
		N	173	173	175	172	175	174	175	175	152
	Frequency of surgery	Correlation Coefficient	.038	.102	-.151*	1.000	.397**	.671**	.125	-.200**	-.039
		Sig. (2-tailed)	.620	.180	.048	.	.000	.000	.098	.008	.636
		N	173	173	172	175	175	175	175	175	152
Length of diagnosis	Correlation Coefficient	-.020	-.061	-.221**	.397**	1.000	.430**	.150*	.008	-.003	
	Sig. (2-tailed)	.790	.422	.003	.000	.	.000	.046	.915	.972	
	N	176	176	175	175	178	177	178	178	154	
Total number of overnight stays in hospital	Correlation Coefficient	.088	.071	-.081	.671**	.430**	1.000	.144	-.142	.044	
	Sig. (2-tailed)	.244	.352	.289	.000	.000	.	.056	.060	.590	
	N	175	175	174	175	177	177	177	177	154	
Age of youngest child in years	Correlation Coefficient	.041	.141	-.047	.125	.150*	.144	1.000	-.081	-.074	
	Sig. (2-tailed)	.592	.063	.535	.098	.046	.056	.	.281	.361	
	N	176	176	175	175	178	177	178	178	154	
Number of children under 16 years living at home	Correlation Coefficient	-.041	-.032	-.001	-.200**	.008	-.142	-.081	1.000	.063	
	Sig. (2-tailed)	.591	.674	.985	.008	.915	.060	.281	.	.436	
	N	176	176	175	175	178	177	178	178	154	
Composite score of division of household labour	Correlation Coefficient	.113	.222**	.256**	-.039	-.003	.044	-.074	.063	1.000	
	Sig. (2-tailed)	.167	.006	.001	.636	.972	.590	.361	.436	.	
	N	152	152	152	152	154	154	154	154	154	

** Correlation is significant at the .01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

Table 8: Correlation matrix for interval level health variables and depression

Correlations

		Total HADS depression score	SIBDQ minus psychological distress	Log of length of symptoms add 10	Have you stayed overnight in hospital in last year	Surgery in the last year	Prescribed regular medication in last year	Prescribed steroids in last year	Prescribed azathioprine in last year	Any other long term illnesses	General perception of health
Total HADS depression score	Pearson Correlation	1	-.722**	.106	.173*	.125	.271**	.179*	.086	.338**	.585**
	Sig. (2-tailed)	.	.000	.160	.021	.097	.000	.017	.258	.000	.000
	N	178	171	176	177	176	176	177	176	177	174
SIBDQ minus psychological distress	Pearson Correlation	-.722**	1	-.143	-.130	-.143	-.252**	-.255**	-.072	-.414**	-.658**
	Sig. (2-tailed)	.000	.	.063	.091	.063	.001	.001	.355	.000	.000
	N	171	171	170	170	169	169	170	169	170	168
Log of length of symptoms add 10	Pearson Correlation	.106	-.143	1	-.042	.061	-.053	-.152*	-.057	.099	.105
	Sig. (2-tailed)	.160	.063	.	.578	.421	.489	.045	.456	.192	.168
	N	176	170	176	176	175	175	176	175	178	173
Have you stayed overnight in hospital in last year	Pearson Correlation	.173*	-.130	-.042	1	.528**	-.046	.120	.017	.069	.061
	Sig. (2-tailed)	.021	.091	.578	.	.000	.545	.112	.827	.360	.424
	N	177	170	176	177	176	176	177	176	177	174
Surgery in the last year	Pearson Correlation	.125	-.143	.061	.528**	1	.020	.117	-.080	.061	.008
	Sig. (2-tailed)	.097	.063	.421	.000	.	.789	.122	.291	.422	.912
	N	176	169	175	176	176	175	176	175	176	173
Prescribed regular medication in last year	Pearson Correlation	.271**	-.252**	-.053	-.046	.020	1	.299**	.280**	.153*	.201**
	Sig. (2-tailed)	.000	.001	.489	.545	.789	.	.000	.000	.042	.008
	N	176	169	175	176	175	176	176	175	176	173
Prescribed steroids in last year	Pearson Correlation	.179*	-.255**	-.152*	.120	.117	.299**	1	.169*	.140	.166*
	Sig. (2-tailed)	.017	.001	.045	.112	.122	.000	.	.025	.063	.029
	N	177	170	176	177	176	176	177	176	177	174
Prescribed azathioprine in last year	Pearson Correlation	.086	-.072	-.057	.017	-.080	.280**	.169*	1	-.025	.076
	Sig. (2-tailed)	.258	.355	.456	.827	.291	.000	.025	.	.746	.319
	N	176	169	175	176	175	175	176	176	176	173
Any other long term illnesses	Pearson Correlation	.338**	-.414**	.099	.069	.061	.153*	.140	-.025	1	.493**
	Sig. (2-tailed)	.000	.000	.192	.360	.422	.042	.063	.746	.	.000
	N	177	170	176	177	176	176	177	176	177	174
General perception of health	Pearson Correlation	.585**	-.658**	.105	.061	.008	.201**	.166*	.076	.493**	1
	Sig. (2-tailed)	.000	.000	.168	.424	.912	.008	.029	.319	.000	.
	N	174	168	173	174	173	173	174	173	174	174

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 9: Correlation matrix for interval level non-health variables and depression

Correlations

		Total HADS depression score	Parent sex	Currently living with a partner	How are you managing financially	Parent age in years	Does partner have any illness etc	Average PTI score - log transformation	Total family support scale score (excluding others)
Total HADS depression score	Pearson Correlation	1	-.070	-.261**	.271**	.021	.025	.604**	-.205**
	Sig. (2-tailed)	.	.353	.000	.000	.783	.759	.000	.009
	N	178	178	178	177	178	156	152	159
Parent sex	Pearson Correlation	-.070	1	.093	-.047	.179*	.021	-.080	.084
	Sig. (2-tailed)	.353	.	.215	.537	.017	.794	.330	.290
	N	178	178	178	177	178	156	152	159
Currently living with a partner	Pearson Correlation	-.261**	.093	1	-.168*	.027	.025	-.195*	.198*
	Sig. (2-tailed)	.000	.215	.	.025	.723	.	.016	.013
	N	178	178	178	177	178	156	152	159
How are you managing financially	Pearson Correlation	.271**	-.047	-.168*	1	-.097	.114	.288**	-.108
	Sig. (2-tailed)	.000	.537	.025	.	.197	.158	.000	.177
	N	177	177	177	177	177	155	152	159
Parent age in years	Pearson Correlation	.021	.179*	.027	-.097	1	.108	.039	-.193*
	Sig. (2-tailed)	.783	.017	.723	.197	.	.182	.636	.015
	N	178	178	178	177	178	156	152	159
Does partner have any illness etc	Pearson Correlation	.025	.021	.025	.114	.108	1	.194*	-.058
	Sig. (2-tailed)	.759	.794	.	.158	.182	.	.023	.492
	N	156	156	156	155	156	156	138	142
Average PTI score - log transformation	Pearson Correlation	.604**	-.080	-.195*	.288**	.039	.194*	1	-.184*
	Sig. (2-tailed)	.000	.330	.016	.000	.636	.023	.	.030
	N	152	152	152	152	152	138	152	139
Total family support scale score (excluding others)	Pearson Correlation	-.205**	.084	.198*	-.108	-.193*	-.058	-.184*	1
	Sig. (2-tailed)	.009	.290	.013	.177	.015	.492	.030	.
	N	159	159	159	159	159	142	139	159

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

a. Cannot be computed because at least one of the variables is constant.

Table 10: Correlation matrix for ordinal level variables and depression

Correlations

			Total HADS depression score	Parent qualification 4 categories	Family socio-economic classification	Frequency of surgery	Length of diagnosis	Total number of overnight stays in hospital	Age of youngest child in years	Number of children under 16 years living at home	Composite score of division of household labour
Spearman's rho	Total HADS depression score	Correlation Coefficient	1.000	.127	.082	.108	.003	.150*	.035	-.032	-.079
		Sig. (2-tailed)	.	.093	.280	.156	.966	.046	.645	.675	.328
		N	178	176	175	175	178	177	178	178	154
Parent qualification 4 categories		Correlation Coefficient	.127	1.000	.430**	.102	-.061	.071	.141	-.032	.222**
		Sig. (2-tailed)	.093	.	.000	.180	.422	.352	.063	.674	.006
		N	176	176	173	173	176	175	176	176	152
Family socio-economic classification		Correlation Coefficient	.082	.430**	1.000	-.151*	-.221**	-.081	-.047	-.001	.256**
		Sig. (2-tailed)	.280	.000	.	.048	.003	.289	.535	.985	.001
		N	175	173	175	172	175	174	175	175	152
Frequency of surgery		Correlation Coefficient	.108	.102	-.151*	1.000	.397**	.671**	.125	-.200**	-.039
		Sig. (2-tailed)	.156	.180	.048	.	.000	.000	.098	.008	.636
		N	175	173	172	175	175	175	175	175	152
Length of diagnosis		Correlation Coefficient	.003	-.061	-.221**	.397**	1.000	.430**	.150*	.008	-.003
		Sig. (2-tailed)	.966	.422	.003	.000	.	.000	.046	.915	.972
		N	178	176	175	175	178	177	178	178	154
Total number of overnight stays in hospital		Correlation Coefficient	.150*	.071	-.081	.671**	.430**	1.000	.144	-.142	.044
		Sig. (2-tailed)	.046	.352	.289	.000	.000	.	.056	.060	.590
		N	177	175	174	175	177	177	177	177	154
Age of youngest child in years		Correlation Coefficient	.035	.141	-.047	.125	.150*	.144	1.000	-.081	-.074
		Sig. (2-tailed)	.645	.063	.535	.098	.046	.056	.	.281	.361
		N	178	176	175	175	178	177	178	178	154
Number of children under 16 years living at home		Correlation Coefficient	-.032	-.032	-.001	-.200**	.008	-.142	-.081	1.000	.063
		Sig. (2-tailed)	.675	.674	.985	.008	.915	.060	.281	.	.436
		N	178	176	175	175	178	177	178	178	154
Composite score of division of household labour		Correlation Coefficient	-.079	.222**	.256**	-.039	-.003	.044	-.074	.063	1.000
		Sig. (2-tailed)	.328	.006	.001	.636	.972	.590	.361	.436	.
		N	154	152	152	152	154	154	154	154	154

*. Correlation is significant at the .05 level (2-tailed).

** Correlation is significant at the .01 level (2-tailed).

Appendix 38

**Bivariate analysis of independent variables selected for inclusion in
regression analysis of HADS data**

		Presence of another illness	Prescribed regular medication	Respondent's work situation	Whether currently living with a partner	Highest qualification
Presence of another illness	<i>Chi-square</i> <i>df</i> <i>Sig.</i>	N/A				
Prescribed regular medication	<i>Chi-square</i> <i>df</i> <i>Sig.</i>	4.14 * 1 .042	N/A			
Respondent's work situation	<i>Chi-square</i> <i>df</i> <i>Sig.</i>	22.22 ** 2 <.001	0.49 2 .781	N/A		
Whether currently living with a partner	<i>Chi-square</i> <i>df</i> <i>Sig.</i>	7.98 ** 1 .005	Not calculated	5.13 2 .08	N/A	
Respondent's highest qualification	<i>Chi-square</i> <i>df</i> <i>Sig.</i>	10.41 2 .005	Not calculated	Not calculated	1.47 2 .48	N/A

Not calculated – this is due to low expected cell counts

Variable	F	Df	Significance
SIBDQ minus psychological symptoms	11.05	2,168	<.001
General perception of health	9.083	2,171	<.001
Financial situation	1.90	2,174	.153
Log of average standardised PTI score	3.55	2,149	.031
Family support	0.397	2,156	.673

Variable	F	Df	Significance
SIBDQ minus psychological symptoms	3.786	3,165	.012
General perception of health	3.149	3,168	.027
Financial situation	6.555	3,171	<.001
Log of average standardised PTI score	Not calculated due to highly skewed distribution		
Family support	1.609	3,154	.190

Table 4: Correlation matrix for independent variables in models of parental depression and anxiety

Correlations

		SIBDQ minus psychological distress	Prescribed regular medication in last year	Any other long term illnesses	General perception of health	How are you managing financially	Average PTI score - log transformation	Total family support scale score (excluding others)	Currently living with a partner
SIBDQ minus psychological distress	Pearson Correlation	1.000	-.252**	-.414**	-.658**	-.369**	-.480**	.184*	.321**
	Sig. (2-tailed)	.	.001	.000	.000	.000	.000	.022	.000
	N	171	169	170	168	171	147	155	171
Prescribed regular medication in last year	Pearson Correlation	-.252**	1.000	.153*	.201**	.035	.117	-.062	-.121
	Sig. (2-tailed)	.001	.	.042	.008	.648	.153	.443	.110
	N	169	176	176	173	175	150	157	176
Any other long term illnesses	Pearson Correlation	-.414**	.153*	1.000	.493**	.071	.223**	-.134	-.212**
	Sig. (2-tailed)	.000	.042	.	.000	.348	.006	.092	.005
	N	170	176	177	174	176	151	158	177
General perception of health	Pearson Correlation	-.658**	.201**	.493**	1.000	.303**	.470**	-.066	-.184*
	Sig. (2-tailed)	.000	.008	.000	.	.000	.000	.415	.015
	N	168	173	174	174	173	148	155	174
How are you managing financially	Pearson Correlation	-.369**	.035	.071	.303**	1.000	.288**	-.108	-.168*
	Sig. (2-tailed)	.000	.648	.348	.000	.	.000	.177	.025
	N	171	175	176	173	177	152	159	177
Average PTI score - log transformation	Pearson Correlation	-.480**	.117	.223**	.470**	.288**	1.000	-.184*	-.195*
	Sig. (2-tailed)	.000	.153	.006	.000	.000	.	.030	.016
	N	147	150	151	148	152	152	139	152
Total family support scale score (excluding others)	Pearson Correlation	.184*	-.062	-.134	-.066	-.108	-.184*	1.000	.198*
	Sig. (2-tailed)	.022	.443	.092	.415	.177	.030	.	.013
	N	155	157	158	155	159	139	159	159
Currently living with a partner	Pearson Correlation	.321**	-.121	-.212**	-.184*	-.168*	-.195*	.198*	1.000
	Sig. (2-tailed)	.000	.110	.005	.015	.025	.016	.013	.
	N	171	176	177	174	177	152	159	178

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Appendix 39

**Testing for moderators in the conceptual model of factors predicting
parent's anxiety and depression**

Testing for interactions effects in the prediction of parental anxiety

Table 1: Family support and parenting difficulty as predictors of anxiety

Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Family support (SS)	.39	.16	.14				
Parenting difficulty (PD)							
Model 2							
Family support (PS)							
Parenting difficulty (PD)	.41	.17	.15	.010	1.587	1,133	.210
SS x PD							

Table 2: Parent sex and parenting difficulty as predictors of anxiety

Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Parent sex (PS)							
Parenting difficulty (PD)	.37	.14	.13				
Model 2							
Parent sex (PS)							
Parenting difficulty (PD)	.37	.14	.12	.000	.03	1,146	.858
PS x PD							

Testing for interactions effects in the prediction of depression

Table 3: Parent sex and parenting difficulty as predictors of depression							
Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Parent sex (PS)	.60	.36	.36				
Parenting difficulty (PD)							
Model 2							
Parent sex (PS)							
Parenting difficulty (PD)							
PS x PD	.61	.37	.35	.002	0.47	1,48	.493

Table 4 Family support and parenting difficulty as predictors of depression							
Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Family support (SS)	.61	.37	.36				
Parenting difficulty (PD)							
Model 2							
Family support (PS)							
Parenting difficulty (PD)	.63	.40	.39	.028	6.228	1,135	.014*
SS x PD							

Testing Interactions in the prediction of parenting difficulty

Table 5: Age of youngest child and perceived severity of symptoms as predictors of parenting difficulty							
Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Severity of symptoms (SSY)	.49	.24	.23				
Age of youngest child (YC)							
Model 2							
Severity of symptoms (SSY)							
Age of youngest child (YC)	.49	.24	.23	.000	.058	1,143	.810
RSIBXYC							

NB Standardised residuals for above regression analysis looks heteroscedastic

Table 6: Age of youngest child and prescribed medication in the last year as predictors of parenting difficulty							
Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Prescribed medication (PM)	.13	.02	.004				
Age of youngest child (YC)							
Model 2							
Prescribed medication (PM)	.17	.03	.010	.012	1.840	1,146	.177
Age of youngest child (YC)							
PMXYC							

Table 7: Age of youngest child and presence of another illness as predictors of parenting difficulty							
Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1							
Presence of another illness (POI)	.23	.05	.04				
Age of youngest child (YC)							
Model 2							
Presence of another illness (POI)							
Age of youngest child (YC)	.23	.05	.03	.001	.163	1,147	.69
POIXYC							

Appendix 40

**Bivariate analysis of parent-reported SDQ total difficulties scores
according to independent variables**

Table 1: ANOVAs to test differences in parent-reported SDQ total difficulties according to categorical independent variables			
Independent variable	F	Df	Significance
Respondent's work situation	3.302	2,118	.040
Partner's work situation	3.447	2,136	.035

Table 2: Independent samples t-test to test differences in parent-reported SDQ total difficulties according to independent variables			
Independent variable	T	Df	Significance
Diagnosis (CD or UC)	.188	133	.851

Table 3: Correlations between parent-reported SDQ total difficulties score for 4-16 year olds and parent health variables

Correlations

		Parent's rating of total difficulties	SIBDQ minus psychological distress	Have you stayed overnight in hospital in last year	Surgery in the last year	Prescribed regular medication in last year	Prescribed steroids in last year	Prescribed azathioprine in last year	Any other long term illnesses	Does participant have ileostomy	Total HADS anxiety score	Total HADS depression score
Parent's rating of total difficulties	Pearson Correlation	1	-.280**	.110	.093	.100	.062	.157	.282**	-.076	.296**	.339**
	Sig. (2-tailed)		.001	.200	.276	.247	.470	.065	.001	.374	.000	.000
	N	139	133	138	138	137	138	138	138	138	138	139
SIBDQ minus psychological distress	Pearson Correlation	-.280**	1	-.130	-.162	-.224**	-.284**	-.053	-.487**	.038	-.462**	-.711**
	Sig. (2-tailed)	.001		.129	.059	.009	.001	.539	.000	.656	.000	.000
	N	133	138	137	137	136	137	137	137	137	137	138
Have you stayed overnight in hospital in last year	Pearson Correlation	.110	-.130	1	.524**	-.074	.127	.019	.022	.167*	-.013	.164*
	Sig. (2-tailed)	.200	.129		.000	.380	.130	.823	.789	.047	.877	.049
	N	138	137	144	144	143	144	144	144	143	143	144
Surgery in the last year	Pearson Correlation	.093	-.162	.524**	1	-.024	.097	-.091	.061	.278**	-.150	.120
	Sig. (2-tailed)	.276	.059	.000		.772	.245	.278	.469	.001	.073	.152
	N	138	137	144	144	143	144	144	144	143	143	144
Prescribed regular medication in last year	Pearson Correlation	.100	-.224**	-.074	-.024	1	.294**	.280**	.234**	-.154	.137	.250**
	Sig. (2-tailed)	.247	.009	.380	.772		.000	.001	.005	.067	.105	.003
	N	137	136	143	143	143	143	143	143	142	142	143
Prescribed steroids in last year	Pearson Correlation	.062	-.284**	.127	.097	.294**	1	.117	.187**	-.006	.032	.187*
	Sig. (2-tailed)	.470	.001	.130	.245	.000		.161	.025	.940	.703	.025
	N	138	137	144	144	143	144	144	144	143	143	144
Prescribed azathioprine in last year	Pearson Correlation	.157	-.053	.019	-.091	.280**	.117	1	.000	-.151	.016	.109
	Sig. (2-tailed)	.065	.539	.823	.278	.001	.161		1.000	.071	.852	.194
	N	138	137	144	144	143	144	144	144	143	143	144
Any other long term illnesses	Pearson Correlation	.282**	-.487**	.022	.061	.234**	.187**	.000	1	.105	.291**	.397**
	Sig. (2-tailed)	.001	.000	.789	.469	.005	.025	1.000		.211	.000	.000
	N	138	137	144	144	143	144	144	144	143	143	144
Does participant have ileostomy	Pearson Correlation	-.076	.038	.167*	.278**	-.154	-.006	-.151	.105	1	-.035	-.005
	Sig. (2-tailed)	.374	.656	.047	.001	.067	.940	.071	.211		.681	.949
	N	138	137	143	143	142	143	143	143	144	143	144
Total HADS anxiety score	Pearson Correlation	.296**	-.462**	-.013	-.150	.137	.032	.016	.291**	-.035	1	.660**
	Sig. (2-tailed)	.000	.000	.877	.073	.105	.703	.852	.000	.681		.000
	N	138	137	143	143	142	143	143	143	143	144	144
Total HADS depression score	Pearson Correlation	.339**	-.711**	.164*	.120	.250**	.187**	.109	.397**	-.005	.660**	1
	Sig. (2-tailed)	.000	.000	.049	.152	.003	.025	.194	.000	.949	.000	
	N	139	138	144	144	143	144	144	144	144	144	145

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 4: Correlations between parent-reported SDQ total difficulties score for 4-16 year olds and other parent variables

Correlations

		Parent's rating of total difficulties	Parent sex	Parent age in years	Currently living with a partner	How are you managing financially	Does partner have any illness etc	LOGPAR	Total family support scale score (excluding others)
Parent's rating of total difficulties	Pearson Correlation	1	-.067	-.277**	-.183*	.270**	.151	.411**	-.038
	Sig. (2-tailed)	.	.432	.001	.031	.001	.099	.000	.669
	N	139	139	139	139	139	121	122	128
Parent sex	Pearson Correlation	-.067	1	.228**	.075	-.108	.020	-.167	.120
	Sig. (2-tailed)	.432	.	.006	.370	.199	.823	.064	.174
	N	139	145	145	145	144	125	124	130
Parent age in years	Pearson Correlation	-.277**	.228**	1	.038	-.135	-.015	-.034	-.161
	Sig. (2-tailed)	.001	.006	.	.653	.107	.870	.704	.067
	N	139	145	145	145	144	125	124	130
Currently living with a partner	Pearson Correlation	-.183*	.075	.038	1	-.200*	. ^a	-.220*	.189*
	Sig. (2-tailed)	.031	.370	.653	.	.016	.	.014	.032
	N	139	145	145	145	144	125	124	130
How are you managing financially	Pearson Correlation	.270**	-.108	-.135	-.200*	1	.086	.302**	-.074
	Sig. (2-tailed)	.001	.199	.107	.016	.	.343	.001	.402
	N	139	144	144	144	144	124	124	130
Does partner have any illness etc	Pearson Correlation	.151	.020	-.015	. ^a	.086	1	.240*	-.008
	Sig. (2-tailed)	.099	.823	.870	.	.343	.	.011	.935
	N	121	125	125	125	124	125	111	115
LOGPAR	Pearson Correlation	.411**	-.167	-.034	-.220*	.302**	.240*	1	-.148
	Sig. (2-tailed)	.000	.064	.704	.014	.001	.011	.	.114
	N	122	124	124	124	124	111	124	115
Total family support scale score (excluding others)	Pearson Correlation	-.038	.120	-.161	.189*	-.074	-.008	-.148	1
	Sig. (2-tailed)	.669	.174	.067	.032	.402	.935	.114	.
	N	128	130	130	130	130	115	115	130

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

^a Cannot be computed because at least one of the variables is constant.

Table 5: Correlations between parent's reported SDQ total difficulties in 4-16 year olds and child interval variables

Correlations

		Parent's rating of total difficulties	child sex	Child age in years	Does child have any illnesses, health problems, disabilities?
Parent's rating of total difficulties	Pearson Correlation	1	.088	-.228**	.192*
	Sig. (2-tailed)	.	.306	.007	.025
	N	139	138	139	136
child sex	Pearson Correlation	.088	1	.017	.106
	Sig. (2-tailed)	.306	.	.836	.210
	N	138	144	144	141
Child age in years	Pearson Correlation	-.228**	.017	1	.101
	Sig. (2-tailed)	.007	.836	.	.232
	N	139	144	145	142
Does child have any illnesses, health problems, disabilities?	Pearson Correlation	.192*	.106	.101	1
	Sig. (2-tailed)	.025	.210	.232	.
	N	136	141	142	142

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Table 6 : Correlations between parent reported SDQ total difficulties in 4-16 year olds total difficulties and ordinal variables

Correlations

			Parent's rating of total difficulties	How many years have you had symptoms	Length of diagnosis	Frequency of overnight stays in hospital	Frequency of surgery	In general would you say your health is	Family socio-economic classification	Parent qualification 4 categories	Composite score of division of household labour	Number of children under 16 years living at home	
Spearman's rho	Parent's rating of total difficulties	Correlation Coefficient	1.000	-.059	-.142	.044	-.036	.180*	.165	.051	.130	-.031	
		Sig. (2-tailed)	.	.494	.095	.610	.673	.036	.055	.551	.160	.714	
		N	139	137	139	138	138	136	137	138	119	139	
	How many years have you had symptoms	Correlation Coefficient	-.059	1.000	.815**	.444**	.354**	.121	-.188*	-.040	.027	-.050	
		Sig. (2-tailed)	.494	.	.000	.000	.000	.154	.025	.640	.767	.553	
		N	137	143	143	143	143	141	141	142	122	143	
	Length of diagnosis	Correlation Coefficient	-.142	.815**	1.000	.409**	.374**	.058	-.225**	-.096	.016	-.105	
		Sig. (2-tailed)	.095	.000	.	.000	.000	.493	.007	.251	.857	.210	
		N	139	143	145	144	144	142	143	144	123	145	
	Frequency of overnight stays in hospital	Correlation Coefficient	.044	.444**	.409**	1.000	.655**	.220**	-.054	-.054	.061	.112	-.186**
		Sig. (2-tailed)	.610	.000	.000	.	.000	.008	.524	.466	.218	.025	
		N	138	143	144	144	144	142	142	143	123	144	
	Frequency of surgery	Correlation Coefficient	-.036	.354**	.374**	.655**	1.000	.085	-.114	.080	-.057	-.226**	
Sig. (2-tailed)		.673	.000	.000	.000	.	.315	.176	.343	.529	.007		
	N	138	143	144	144	144	142	142	143	123	144		
In general would you say your health is	Correlation Coefficient	.180*	.121	.058	.220**	.085	1.000	.122	.233**	.011	-.062		
	Sig. (2-tailed)	.036	.154	.493	.008	.315	.	.150	.006	.905	.464		
	N	136	141	142	142	142	142	140	141	121	142		
Family socio-economic classification	Correlation Coefficient	.165	-.188*	-.225**	-.054	-.114	.122	1.000	.393**	.225*	.082		
	Sig. (2-tailed)	.055	.025	.007	.524	.176	.150	.	.000	.013	.328		
	N	137	141	143	142	142	140	143	142	122	143		
Parent qualification 4 categories	Correlation Coefficient	.051	-.040	-.096	.061	.080	.233**	.393**	1.000	.201*	-.078		
	Sig. (2-tailed)	.551	.640	.251	.466	.343	.006	.000	.	.027	.355		
	N	138	142	144	143	143	141	142	144	122	144		
Composite score of division of household labour	Correlation Coefficient	.130	.027	.016	.112	-.057	.011	.225*	.201*	1.000	.024		
	Sig. (2-tailed)	.160	.767	.857	.218	.529	.905	.013	.027	.	.791		
	N	119	122	123	123	123	121	122	122	123	123		
Number of children under 16 years living at home	Correlation Coefficient	-.031	-.050	-.105	-.186**	-.226**	-.062	.082	-.078	.024	1.000		
	Sig. (2-tailed)	.714	.553	.210	.025	.007	.464	.328	.355	.791	.		
	N	139	143	145	144	144	142	143	144	123	145		

*. Correlation is significant at the .05 level (2-tailed).

** . Correlation is significant at the .01 level (2-tailed).

Appendix 41

Bivariate analysis of independent variables selected for inclusion in regression analysis of parent-reported SDQ total difficulties scores

Table 1: Chi-square analysis of independent variables in model of 4-16 year olds parent – reported SDQ total difficulties score

		Does child have an illness, health problem or disability?	Whether currently living with a partner	Does parent have another illness, health problem or disability?
Does child have an illness, health problem or disability	<i>Chi- square</i> <i>df</i> <i>Sig.</i>	N/A		
Whether currently living with a partner	<i>Chi- square</i> <i>df</i> <i>Sig.</i>	.303 1 .582	N/A	
Does parent have another illness, health problem or disability	<i>Chi- square</i> <i>df</i> <i>Sig.</i>	3.344 1 .067	10.286 1 .001	N/A

Table 2: Correlations between independent variables in model of parent-reported SDQ data for 4-16 year olds

Correlations

		SIBDQ minus psychological distress	Any other long term illnesses	Total HADS anxiety score	Total HADS depression score	How are you managing financially	Log of standardised PTI score	Child age in years	Does child have any illnesses, health problems, disabilities?	Currently living with a partner
SIBDQ minus psychological distress	Pearson Correlation	1	-.487**	-.462**	-.711**	-.361**	-.468**	-.159	-.039	.364**
	Sig. (2-tailed)	.	.000	.000	.000	.000	.000	.062	.653	.000
	N	138	137	137	138	138	119	138	135	138
Any other long term illnesses	Pearson Correlation	-.487**	1	.291**	.397**	.142	.190*	.077	.154	-.267**
	Sig. (2-tailed)	.000	.	.000	.000	.092	.035	.360	.068	.001
	N	137	144	143	144	143	123	144	141	144
Total HADS anxiety score	Pearson Correlation	-.462**	.291**	1	.660**	.293**	.361**	.058	.150	-.224**
	Sig. (2-tailed)	.000	.000	.	.000	.000	.000	.493	.076	.007
	N	137	143	144	144	143	123	144	141	144
Total HADS depression score	Pearson Correlation	-.711**	.397**	.660**	1	.286**	.631**	.067	.107	-.293**
	Sig. (2-tailed)	.000	.000	.000	.	.001	.000	.424	.206	.000
	N	138	144	144	145	144	124	145	142	145
How are you managing financially	Pearson Correlation	-.361**	.142	.293**	.286**	1	.302**	-.065	-.005	-.200*
	Sig. (2-tailed)	.000	.092	.000	.001	.	.001	.436	.954	.016
	N	138	143	143	144	144	124	144	141	144
Log of standardised PTI score	Pearson Correlation	-.468**	.190*	.361**	.631**	.302**	1	-.050	.010	-.220*
	Sig. (2-tailed)	.000	.035	.000	.000	.001	.	.583	.915	.014
	N	119	123	123	124	124	124	124	122	124
Child age in years	Pearson Correlation	-.159	.077	.058	.067	-.065	-.050	1	.101	-.044
	Sig. (2-tailed)	.062	.360	.493	.424	.436	.583	.	.232	.603
	N	138	144	144	145	144	124	145	142	145
Does child have any illnesses, health problems, disabilities?	Pearson Correlation	-.039	.154	.150	.107	-.005	.010	.101	1	-.046
	Sig. (2-tailed)	.653	.068	.076	.206	.954	.915	.232	.	.585
	N	135	141	141	142	141	122	142	142	142
Currently living with a partner	Pearson Correlation	.364**	-.267**	-.224**	-.293**	-.200*	-.220*	-.044	-.046	1
	Sig. (2-tailed)	.000	.001	.007	.000	.016	.014	.603	.585	.
	N	138	144	144	145	144	124	145	142	145

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Appendix 42

**Testing for moderators in the conceptual model of factors predicting
parent-reported SDQ total difficulties scores**

Testing for interactions effects in the prediction of parenting difficulty

Table 1: Child's age and SIBDQ minus psychological distress as predictors of parenting difficulties with 4-16 year olds

Independent variable	R	R square	R square change	F change	df	Sig. F change
Model 1 Child's age (CA) SIBDQ minus psych (SIBDQM)	.49	.24				
Model 2 Child's age (CA) SIBDQ minus psych (SIBDQM) CAXSIBDQM	.49	.24	.002	.304	1,115	.582

Table 2: Child's age and whether parent has an illness other than IBD as predictors of parenting difficulties with 4-16 year olds

Independent variable	R	R square	R square change	F change	df	Sig. F change
Model 1 Child's age (CA) If parent has other illness (POILL)	0.20	.04				
Model 2 Child's age (CA) If parent has other illness (POILL) CAXPOILL	0.20	.04	.001	.130	1,119	.720

Testing for interactions effects in the prediction of parent-reported SDQ total difficulties score

Table 3: Social support and parental depression as predictors of parent-rated total difficulties SDQ scores in 4-16 year olds

Independent variable	R	R square	R square change	F change	df	Sig. F change
Model 1 Social support (SP) Parental depression (PH)	.32	.10				
Model 2 Social support (SP) Parental depression (PH) SPXPH	.33	.10	.002	.262	1,124	.610

Table 4: Social support and parental anxiety as predictors of parent-rated total difficulties SDQ score in 4-16 year olds

Independent variable	R	R square	R square change	F change	df	Sig. of F change
Model 1						
Social support (SP)	.30	.09				
Parental anxiety (PA)						
Model 2						
Social support (SP)	.30	.09	.000	.018	1,123	.894
Parental anxiety (PA)						
SPXPA						

Table 5: Social support and parenting difficulties as predictors of parent-rated total difficulties SDQ scores in 4-16 year olds

Independent variable	R	R square	R square change	F change	df	Sig. of F change
Model 1						
Social support (SP)	.40	.16				
Log standardised PTI score (LSPTI)						
Model 2						
Social support (SP)	.40	.16	.000	.044	1,110	.833
Log standardised PTI score (LSPTI)						
SPXLSPTI						

Table 6: Social support and parental hospitalisation in the last year as predictors of parent-rated total difficulties SDQ scores in 4-16 year olds

Independent variable	R	R square	R square change	F change	df	Sig. of F change
Model 1						
Social support (SP)	.11	.01				
Hospital stay (H)						
Model 2						
Social support (SP)	.15	.02	.012	1.543	1,123	.217
Hospital stay (H)						
SPXH						

Appendix 43

**Tests on normality of distribution of ordinal and interval level
variables in sub-sample of child aged 11-16 years per family**

Table 1: Tests on variables based on random sample of one child aged 11-16 years per family

Scale	Skewness	Standard error	kurtosis	Standard error	Outliers
<i>Health of parent with IBD</i>					
Reduced SIBDQ	-0.17	0.32	-0.42	0.63	no
Duration of symptoms	0.39	0.31	-0.40	0.62	no
Time since diagnosis	-1.10*	0.31	0.27	0.61	no
Frequency of hospitalisations for IBD during life	0.13	0.31	-1.48*	0.61	no
Frequency of surgery for IBD	0.84	0.31	-0.61	0.62	no
General perception of health	-0.28	0.31	-0.64	0.62	n=1
<i>Socio-demographics</i>					
Perception of financial situation	0.33	0.31	-0.67	0.61	n=4
Parent's highest educational qualification	-1.06*	0.31	0.39	0.62	scores 1,3,4 31% of scores
Age of parent	0.57	0.31	-0.16	0.61	no
Number of children under 16 years living at home	0.68	0.31	0.19	0.61	n=3
Parent's responsibility for domestic labour	-0.75	0.33	-0.66	0.66	no
Adolescent PTI score	0.83	0.33	0.07	0.65	n=1
Log of adolescent PTI score	-.043	.333	-1.172	0.656	no
Family support	0.60	0.32	0.98	0.64	n=3
HADS anxiety score	0.44	0.31	-0.42	0.61	No
HADS depression score	0.60	0.31	0.66	0.61	n=1
<i>Parent's SDQ data</i>					
Total difficulties score	0.93	0.32	0.13	0.63	N=1
<i>Self-report SDQ data</i>					
Total difficulties score	0.37	0.32	-0.06	0.64	n=1
Child's age	.030	-.311	-1.252	.613	no
Child's perception of seriousness of illness	-0.47	0.32	1.21	0.62	scores < or >2 31.6% of scores
Child's time spent in a week doing household chores	-0.12	0.31	5.49	0.61	no
Child's total involvement with tasks to help parent	0.61	0.33	1.028	0.656	n=1
Child's total social activity	-0.55	0.31	-0.36	0.61	n=1

Appendix 44

Effect of transformations- data used in regression analysis of self-reported SDQ total difficulties

Successful transformations

Log transformation improved the distribution of the following variables:

- adolescent PTI scores (skewness= $-.043$, standard error = $.333$; kurtosis = -1.172 ; standard error = 0.656).

Unsuccessful transformations

Variables used in regression analysis, not improved by transformation, and therefore treated as ordinal level data were:

- number of years the parent had been experiencing symptoms of IBD
- length of diagnosis
- frequency of surgery
- frequency of overnight stays in hospital
- frequency of attending outpatient clinic
- general perception of health
- division of household labour
- number of children under the age of 16 living at home
- family socio-economic classification
- number of children under 16 living at home

Appendix 45

**Bivariate analysis of self-reported SDQ total difficulties scores
according to independent variables**

Table 1: ANOVAs to test differences in self-reported SDQ total difficulties according to categorical independent variables

Independent variable	F	Df	Significance
Respondent's work situation	1.51	2,51	.860
Partner's work situation	1.48	2,46	.238
Child's perception of housework	1.25	2,51	.296

Table 2: Independent samples t-test to test differences in self-reported SDQ total difficulties according to independent variables

Independent variable	T	Df	Significance
Diagnosis (CD or UC)	-.38	51	-.70

Table 3: Correlations between self-report SDQ total difficulties score and parent health variables

		Correlations										
		Self-rating of total difficulties	SIBDQ minus psychological distress	Have you stayed overnight in hospital in last year	Surgery in the last year	Prescribed regular medication in last year	Prescribed steroids in last year	Prescribed azathioprine in last year	Any other long term illnesses	Does participant have ileostomy	Total HADS anxiety score	Total HADS depression score
Self-rating of total difficulties	Pearson Correlation	1	-.114	.095	.137	.029	-.058	.137	.130	-.117	.087	.319*
	Sig. (2-tailed)	.	.430	.494	.324	.836	.677	.324	.349	.400	.530	.019
	N	54	50	54	54	54	54	54	54	54	54	54
SIBDQ minus psychological distress	Pearson Correlation	-.114	1	-.172	-.377**	-.170	-.283*	-.088	-.500**	-.044	-.353**	-.732**
	Sig. (2-tailed)	.430	.	.210	.005	.215	.037	.522	.000	.749	.008	.000
	N	50	55	55	55	55	55	55	55	55	55	55
Have you stayed overnight in hospital in last year	Pearson Correlation	.095	-.172	1	.533**	-.114	.018	.150	.150	.168	-.142	.130
	Sig. (2-tailed)	.494	.210	.	.000	.389	.895	.258	.258	.204	.284	.327
	N	54	55	59	59	59	59	59	59	59	59	59
Surgery in the last year	Pearson Correlation	.137	-.377**	.533**	1	.129	.090	-.026	.153	.319*	-.221	.188
	Sig. (2-tailed)	.324	.005	.000	.	.330	.496	.847	.248	.014	.093	.155
	N	54	55	59	59	59	59	59	59	59	59	59
Prescribed regular medication in last year	Pearson Correlation	.029	-.170	-.114	.129	1	.294*	.216	.077	-.090	-.031	.137
	Sig. (2-tailed)	.836	.215	.389	.330	.	.024	.101	.561	.497	.815	.302
	N	54	55	59	59	59	59	59	59	59	59	59
Prescribed steroids in last year	Pearson Correlation	-.058	-.283*	.018	.090	.294*	1	.176	.246	-.034	-.041	.129
	Sig. (2-tailed)	.677	.037	.895	.496	.024	.	.182	.060	.800	.760	.331
	N	54	55	59	59	59	59	59	59	59	59	59
Prescribed azathioprine in last year	Pearson Correlation	.137	-.088	.150	-.026	.216	.176	1	.216	-.012	.074	.098
	Sig. (2-tailed)	.324	.522	.258	.847	.101	.182	.	.100	.928	.578	.458
	N	54	55	59	59	59	59	59	59	59	59	59
Any other long term illnesses	Pearson Correlation	.130	-.500**	.150	.153	.077	.246	.216	1	.089	.058	.298*
	Sig. (2-tailed)	.349	.000	.258	.248	.561	.060	.100	.	.500	.664	.022
	N	54	55	59	59	59	59	59	59	59	59	59
Does participant have ileostomy	Pearson Correlation	-.117	-.044	.168	.319*	-.090	-.034	-.012	.089	1	-.150	-.075
	Sig. (2-tailed)	.400	.749	.204	.014	.497	.800	.928	.500	.	.257	.570
	N	54	55	59	59	59	59	59	59	59	59	59
Total HADS anxiety score	Pearson Correlation	.087	-.353**	-.142	-.221	-.031	-.041	.074	.058	-.150	1	.590**
	Sig. (2-tailed)	.530	.008	.284	.093	.815	.760	.578	.664	.257	.	.000
	N	54	55	59	59	59	59	59	59	59	59	59
Total HADS depression score	Pearson Correlation	.319*	-.732**	.130	.188	.137	.129	.098	.298*	-.075	.590**	1
	Sig. (2-tailed)	.019	.000	.327	.155	.302	.331	.458	.022	.570	.000	.
	N	54	55	59	59	59	59	59	59	59	59	59

*. Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Table 4: Correlations between self-report SDQ total difficulties and other parent variables

Correlations

		Self-rating of total difficulties	Sex of parent with IBD	Parent age in years	Whether currently living with a partner	Financial situation	Does partner have any illness etc	log of adolescent difficulties excluding other difficulties with constant added	Total family support scale score (excluding others)
Self-rating of total difficulties	Pearson Correlation	1	.184	-.086	-.173	.171	.126	.327*	-.088
	Sig. (2-tailed)	.	.183	.538	.212	.215	.387	.027	.548
	N	54	54	54	54	54	49	46	49
Sex of parent with IBD	Pearson Correlation	.184	1	.360**	.003	.119	.167	-.170	-.085
	Sig. (2-tailed)	.183	.	.005	.985	.370	.231	.234	.543
	N	54	59	59	59	59	53	51	53
Parent age in years	Pearson Correlation	-.086	.360**	1	.021	-.176	.027	-.168	-.382**
	Sig. (2-tailed)	.538	.005	.	.873	.183	.850	.238	.005
	N	54	59	59	59	59	53	51	53
Whether currently living with a partner	Pearson Correlation	-.173	.003	.021	1	-.117	. ^a	-.232	.168
	Sig. (2-tailed)	.212	.985	.873	.	.376	.	.102	.230
	N	54	59	59	59	59	53	51	53
Financial situation	Pearson Correlation	.171	.119	-.176	-.117	1	.104	.396**	-.139
	Sig. (2-tailed)	.215	.370	.183	.376	.	.460	.004	.321
	N	54	59	59	59	59	53	51	53
Does partner have any illness etc	Pearson Correlation	.126	.167	.027	. ^a	.104	1	.259	-.030
	Sig. (2-tailed)	.387	.231	.850	.	.460	.	.075	.842
	N	49	53	53	53	53	53	48	48
log of adolescent difficulties excluding other difficulties with constant added	Pearson Correlation	.327*	-.170	-.168	-.232	.396**	.259	1	-.189
	Sig. (2-tailed)	.027	.234	.238	.102	.004	.075	.	.202
	N	46	51	51	51	51	48	51	47
Total family support scale score (excluding others)	Pearson Correlation	-.088	-.085	-.382**	.168	-.139	-.030	-.189	1
	Sig. (2-tailed)	.548	.543	.005	.230	.321	.842	.202	.
	N	49	53	53	53	53	48	47	53

*. Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

a. Cannot be computed because at least one of the variables is constant.

Table 5: Correlations between self-report SDQ total difficulties score and child interval variables

Correlations

		Self-rating of total difficulties	Child's sex	Child age in years	Does child have any illnesses, health problems, disabilities	TOTHELP	missed school because parent unwell
Self-rating of total difficulties	Pearson Correlation	1	-.029	-.148	.327*	-.086	.312*
	Sig. (2-tailed)	.	.836	.287	.022	.559	.021
	N	54	54	54	49	48	54
Child's sex	Pearson Correlation	-.029	1	-.033	.119	-.021	.102
	Sig. (2-tailed)	.836	.	.806	.392	.885	.440
	N	54	59	59	54	51	59
Child age in years	Pearson Correlation	-.148	-.033	1	-.082	.353*	.153
	Sig. (2-tailed)	.287	.806	.	.554	.011	.246
	N	54	59	59	54	51	59
Does child have any illnesses, health problems, disabilities	Pearson Correlation	.327*	.119	-.082	1	-.014	.184
	Sig. (2-tailed)	.022	.392	.554	.	.924	.182
	N	49	54	54	54	46	54
TOTHELP	Pearson Correlation	-.086	-.021	.353*	-.014	1	.086
	Sig. (2-tailed)	.559	.885	.011	.924	.	.549
	N	48	51	51	46	51	51
missed school because parent unwell	Pearson Correlation	.312*	.102	.153	.184	.086	1
	Sig. (2-tailed)	.021	.440	.246	.182	.549	.
	N	54	59	59	54	51	59

*. Correlation is significant at the 0.05 level (2-tailed).

Table 6: Correlations between self-report SDQ total difficulties score and ordinal variables

		Correlations												
		Self-rating of total difficulties	Family socio-economic classification	Parent's highest qualification (4 category scheme)	Frequency of surgery	How much had you talked about illness	How serious is the illness	Time in a week spent doing chores	Total social activity score	talk to Mum	talk to Dad	quarrel with Mum	quarrel with Dad	
Spearman's rho	Self-rating of total difficulties	Correlation Coefficient Sig. (2-tailed) N	1.000 .911 54	.016 .911 54	-.049 .726 53	-.113 .419 53	-.270 .050 53	-.178 .208 52	-.061 .663 54	-.094 .501 54	.352** .009 54	.490** .000 48	-.282* .039 54	-.140 .347 47
	Family socio-economic classification	Correlation Coefficient Sig. (2-tailed) N	.016 .911 54	1.000 .911 58	.400** .002 57	-.206 .124 57	-.069 .611 57	-.033 .810 56	-.004 .979 58	.189 .154 58	-.014 .915 57	.016 .912 51	-.097 .468 58	-.025 .860 51
	Parent's highest qualification (4 category scheme)	Correlation Coefficient Sig. (2-tailed) N	-.049 .726 53	.400** .002 57	1.000 .002 58	-.049 .719 57	-.069 .610 57	.212 .116 56	.173 .195 58	.157 .239 58	-.162 .230 57	-.020 .890 51	.098 .486 58	.041 .776 51
	Frequency of surgery	Correlation Coefficient Sig. (2-tailed) N	-.113 .419 53	-.206 .124 57	-.049 .719 57	1.000 .050 58	.261 .082 57	.235 .062 56	.040 .765 58	-.133 .320 58	-.169 .210 57	-.150 .293 51	.206 .121 58	-.111 .439 51
	How much had you talked about illness	Correlation Coefficient Sig. (2-tailed) N	-.270 .050 53	-.069 .611 57	-.069 .610 57	.261 .050 57	1.000 .011 58	.336* .011 57	.069 .605 58	.045 .739 58	-.543** .000 57	-.376** .007 51	.043 .748 58	-.247 .080 51
	How serious is the illness	Correlation Coefficient Sig. (2-tailed) N	-.178 .208 52	-.033 .810 56	.212 .116 56	.235 .082 56	.336* .011 57	1.000 .482 57	-.095 .482 57	.162 .229 57	-.145 .285 56	.097 .497 51	.230 .086 57	-.080 .576 51
	Time in a week spent doing chores	Correlation Coefficient Sig. (2-tailed) N	-.061 .663 54	-.004 .979 58	.173 .195 58	.040 .765 58	.069 .605 58	-.095 .482 57	1.000 .293 59	-.139 .293 59	-.099 .458 58	-.073 .605 52	.085 .524 59	-.078 .581 52
	Total social activity score	Correlation Coefficient Sig. (2-tailed) N	-.094 .501 54	.189 .154 58	.157 .239 58	-.133 .320 58	.045 .739 58	.162 .229 57	1.000 .293 59	-.026 .844 58	-.089 .531 52	.004 .977 59	-.096 .497 52	
	talk to Mum	Correlation Coefficient Sig. (2-tailed) N	.352** .009 54	-.014 .915 57	-.162 .230 57	-.169 .210 57	-.543** .000 57	-.145 .285 58	-.099 .458 58	-.026 .844 58	1.000 .000 58	.534** .000 52	-.248 .081 58	.277* .049 51
	talk to Dad	Correlation Coefficient Sig. (2-tailed) N	.490** .000 48	.016 .912 51	-.020 .890 51	-.150 .293 51	-.376** .007 51	.097 .497 51	-.073 .605 52	-.089 .531 52	.534** .000 52	1.000 .000 52	-.064 .654 52	-.136 .340 51
	quarrel with Mum	Correlation Coefficient Sig. (2-tailed) N	-.282* .039 54	-.097 .468 58	.098 .468 58	.206 .121 58	.043 .748 58	.230 .086 57	.085 .524 59	.004 .977 59	-.248 .061 58	-.064 .654 52	1.000 .000 59	.275* .049 52
	quarrel with Dad	Correlation Coefficient Sig. (2-tailed) N	-.140 .347 47	-.025 .860 51	.041 .776 51	-.111 .439 51	-.247 .080 51	-.080 .576 51	-.078 .581 52	-.096 .497 52	.277* .049 51	-.136 .340 51	.275* .049 52	1.000 .000 52

** Correlation is significant at the .01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

Appendix 46

**Bivariate analysis of independent variables selected for inclusion
in regression analysis of self-reported SDQ total difficulties
scores**

Table 1: Pearson correlations between independent variables in model based on self-report SDQ data

Correlations

		Total HADS depression score	log of adolescent difficulties excluding other difficulties with constant added	Does child have any illnesses, health problems, disabilities	missed school because parent unwell
Total HADS depression score	Pearson Correlation	1	.732**	.070	.103
	Sig. (2-tailed)	.	.000	.615	.436
	N	59	51	54	59
log of adolescent difficulties excluding other difficulties with constant added	Pearson Correlation	.732**	1	.123	-.112
	Sig. (2-tailed)	.000	.	.415	.435
	N	51	51	46	51
Does child have any illnesses, health problems, disabilities	Pearson Correlation	.070	.123	1	.184
	Sig. (2-tailed)	.615	.415	.	.182
	N	54	46	54	54
missed school because parent unwell	Pearson Correlation	.103	-.112	.184	1
	Sig. (2-tailed)	.436	.435	.182	.
	N	59	51	54	59

** . Correlation is significant at the 0.01 level (2-tailed).

Table 2: Correlations between independent ordinal variables in model based on self-report SDQ data

			Correlations							
			Total HADS depression score	log of adolescent difficulties excluding other difficulties with constant added	Does child have any illnesses, health problems, disabilities	missed school because parent unwell	How much had you talked about illness	talk to Dad	talk to Mum	quarrel with Mum
Spearman's rho	Total HADS depression score	Correlation Coefficient	1.000	.771**	.119	.029	.087	.270	-.087	-.261*
		Sig. (2-tailed)	.	.000	.391	.825	.516	.053	.518	.046
		N	59	51	54	59	58	52	58	59
	log of adolescent difficulties excluding other difficulties with constant added	Correlation Coefficient	.771**	1.000	.134	-.101	-.106	.328*	.052	-.344*
		Sig. (2-tailed)	.000	.	.373	.481	.466	.026	.719	.013
		N	51	51	46	51	50	46	50	51
	Does child have any illnesses, health problems, disabilities	Correlation Coefficient	.119	.134	1.000	.184	-.019	.301*	.181	.131
		Sig. (2-tailed)	.391	.373	.	.182	.892	.038	.195	.347
		N	54	46	54	54	53	48	53	54
	missed school because parent unwell	Correlation Coefficient	.029	-.101	.184	1.000	.063	.095	.136	-.226
		Sig. (2-tailed)	.825	.481	.182	.	.641	.505	.309	.085
		N	59	51	54	59	58	52	58	59
	How much had you talked about illness	Correlation Coefficient	.087	-.106	-.019	.063	1.000	-.376**	-.543**	.043
		Sig. (2-tailed)	.516	.466	.892	.641	.	.007	.000	.746
		N	58	50	53	58	58	51	57	58
	talk to Dad	Correlation Coefficient	.270	.328*	.301*	.095	-.376**	1.000	.534**	-.064
		Sig. (2-tailed)	.053	.026	.038	.505	.007	.	.000	.654
		N	52	46	48	52	51	52	52	52
	talk to Mum	Correlation Coefficient	-.087	.052	.181	.136	-.543**	.534**	1.000	-.248
		Sig. (2-tailed)	.518	.719	.195	.309	.000	.000	.	.061
		N	58	50	53	58	57	52	58	58
	quarrel with Mum	Correlation Coefficient	-.261*	-.344*	.131	-.226	.043	-.064	-.248	1.000
		Sig. (2-tailed)	.046	.013	.347	.085	.746	.654	.061	.
		N	59	51	54	59	58	52	58	59

** Correlation is significant at the .01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

Appendix 47

**Testing for moderators in the conceptual model of factors
predicting self-reported SDQ total difficulties scores**

Testing for interactions effects in the prediction of self-reported SDQ total difficulties scores

Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1 Family support (SP) Log adolescent PTI score (AD)	.36	.13	.088				
Model 2 Family support (SP) Log adolescent PTI score (AD) SPXAD	.43	.18	.122	.05	2.555	1,39	.118

Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1 Family support (SP) Depression (D)	.33	.11	.073				
Model 2 Family support (SP) Depression (PD) SPXD	.33	.11	.053	.001	.042	1,45	.839

Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. of F change
Model 1 Family support (SP) Anxiety (A)	.11	.01	-.03				
Model 2 Family support (SP) Anxiety (A) SPXA	.11	.01	-.05	.000	.000	1,45	.999

Independent variable	R	R square	Adjusted R square	R square change	F change	Df	Sig. F change
Model 1 Family support (SP) Hospital stay (H)	.14	.02	-.02				
Model 2 Family support (SP) Hospital stay (H) SPXH	.14	.02	-.04	.000	.006	1,45	.940

Appendix 48

Report on Study 2 for children aged 6-10 years

**WHEN MUM OR DAD
FEELS ILL**

REPORT FOR YOUNG PEOPLE

Suzanne Mukherjee,
Department of Health Sciences, University of York,
January 2002

INTRODUCTION

This report is about what life is like for children and young people when they have a Mum or Dad who is unwell some of the time. This is because they have an illness that gives them an upset stomach and makes them have to go to the toilet a lot.

The report is based on a project carried out in 2001. Twenty-three children and young people, from 15 different families, took part by talking to a researcher. They also drew pictures, diagrams and graphs. Some of these drawings are included in this report.

When researchers write reports they often do not use people's real names. This way everything is kept private. The young people who took part in this project were asked if they would like to make up a code name for themselves. Most people did think of a code name, or asked the researcher to think of a code name for them. A few people wanted their real name to be used. These names are:

<i>Abigail</i>	<i>Dave</i>	<i>James 1</i>	<i>Sam</i>	<i>Sweet Pea</i>
<i>Anna</i>	<i>Ginger</i>	<i>James 2</i>	<i>Sarah</i>	<i>Victoria</i>
<i>Becky</i>	<i>Grace</i>	<i>Lucy</i>	<i>Shaggy</i>	<i>Vicky</i>
<i>Charles</i>	<i>Hanna</i>	<i>Luke</i>	<i>Sid Salmon</i>	
<i>Claire</i>	<i>Jack</i>	<i>Rosie</i>	<i>Stephanie</i>	

If you took part in the project, hopefully you will recognise yourself on this list!

Three people were *advisors* to the project. They helped the researcher:

- check that the questions she was asking young people were easy to understand
- think of ways of making the project fun to take part in
- write information leaflets about the project

The advisors' code names were *Gary Moor*, *N8* and *Y2K*

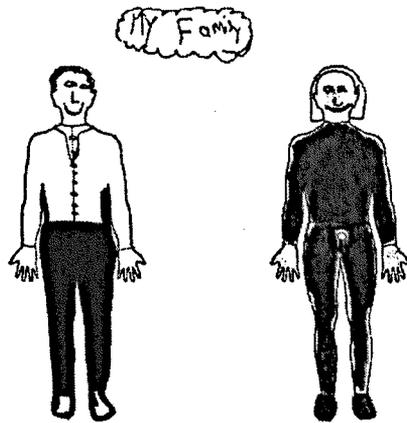
One young person took part in the project *and* was an advisor. Her code name was *Sweet Pea*.

Thank you to all the young people who participated in the project. Without their help, this report could not have been written.

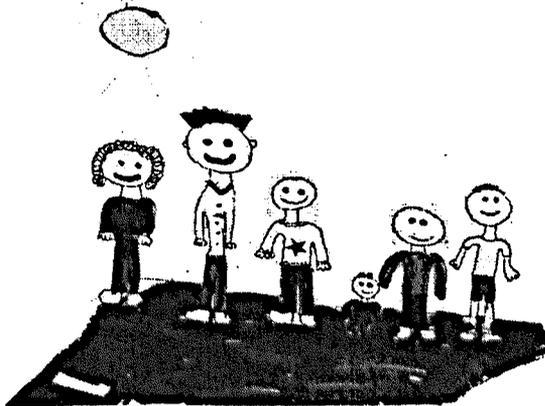
Suzanne Mukherjee

YOUNG PEOPLE WHO TOOK PART IN THE PROJECT

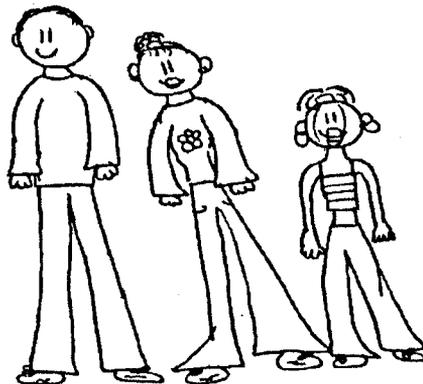
The youngest person who took part in the project was six years old. The oldest was twenty. Most people lived with their Mum and Dad, but five people lived with their Mum and step-Dad, two with their Mum, and one with their Dad.



Eighteen people had a brother or sister living at home.



Five young people did not have a brother or sister.



In their spare time, most people enjoyed doing things at home or near where they lived. They talked about listening to music, computer games, going out on their bike, playing with their brother or sister, playing on scooters, playing in the garden, watching television, drawing, sunbathing, and playing their guitar or piano.



They also liked lots of different sports- skateboarding, football, snooker, volleyball, table tennis, tennis, body boarding, golf, fishing, cricket, and swimming.



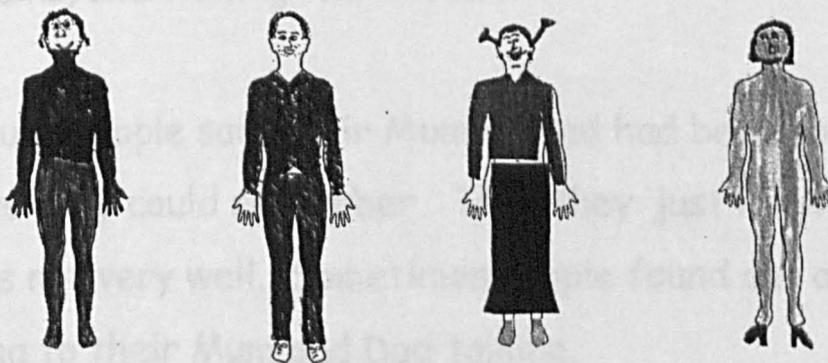
Two young people were members of a group or club (drama club and army cadets). Another helped out with Cubs. Almost everyone mentioned meeting up with friends.

Young people also spent some of their spare time doing things with their Mum, Dad, brothers and sisters. In the box below are the things people said they did at weekends and during holidays.

FAMILY ACTIVITIES		
Shopping	Going 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	

Some people also spent time with other relatives - cousins, grandparents, aunts and uncles.

WHAT IS YOUR MUM OR DAD LIKE?



Everyone was asked to describe their Mum or Dad (the one who was sometimes unwell). Often they used words like 'nice' and 'kind'. Lots of people talked about what a good parent their Mum or Dad was. One young person was not very close to his parent when he

was young, but they had grown closer as he had got older. A few people mentioned things they did not like about their parent.

These were:

- being made to tidy their room
- having to ring to say where you are when out with friends
- when a parent does not stand up for him/herself
- when a parent teases you
- when a parent gets cross and bad tempered

WHAT YOUNG PEOPLE KNEW ABOUT THEIR MUM OR DAD'S ILLNESS

Some people said they did not know anything about their parent's health. Others knew quite a bit.

Young people found out about their parent's illness in different ways. Sometimes a Mum or Dad suddenly became ill, so they noticed their parent going to the toilet more, complaining of stomach pains, and visiting the doctor.

Lots of young people said their Mum or Dad had been poorly for as far back as they could remember. Then they 'just knew' their parent was not very well. Sometimes people found out about things by listening to their Mum and Dad talking.

IS IT SERIOUS OR NOT?

Four young people said their parent's illness was *not at all serious*. Mostly this was because their Mum or Dad was not ill very often.

Five young people thought that their parent's illness was *serious*.

Reasons for this were:

- Mum or Dad could have been very ill, but they were lucky to get treatment quickly
- being ill got in the way of things people wanted to do
- because Mum or Dad might have to go into hospital
- some people worried that their Mum or Dad might die.

Other young people felt the illness was *both serious and not serious*. This was because they knew their parent would *not* die from the illness, but it did get in the way of things they wanted to do.

TALKING TO OTHER PEOPLE

Some parents never talked to their children about what was happening. Others told them everything that happened. Five young people said they preferred *not to talk* to their Mum or Dad about their health. The reasons were:

- it is embarrassing
- it might be upsetting
- they did not want their parent to find out they were upset about it
- they did not think their parents wanted to talk about it

Four girls said they spoke to friends when they were upset or worried about their parent. Other people did not want to talk to friends. Sometimes this was because their parent was not very ill. Others said their friends would not understand, or they worried that friends would make fun of them.

WHAT HAPPENS WHEN MUM OR DAD IS NOT WELL?

Six young people felt that their parent's health *made no difference* to their life.

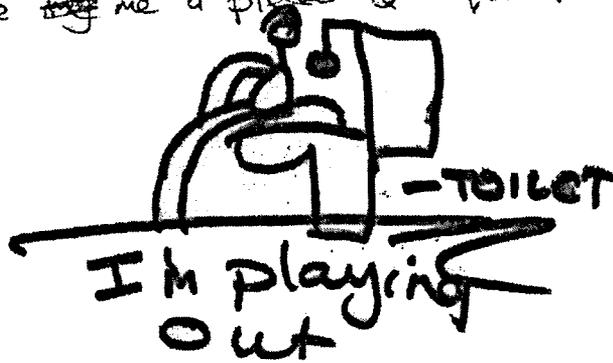
Three young people were able to think of *good things that happened* when their Mum or Dad was ill. These were:

- their parent would read to them when ill in bed
- very occasionally you were allowed to make your own dinner
- people in the family had become closer

Young people also talked about *things that were not so good* about their Mum or Dad being unwell. These were:

- not going out as much with your family
- sometimes the family goes out for the day, or on holiday, but Mum or Dad has to stay at home
- not going out as much with friends
- things don't get done around the house
- you have to be quiet and well-behaved
- Mum or Dad does not talk as much
- people get cross and bad tempered
- having to wait around in hospitals

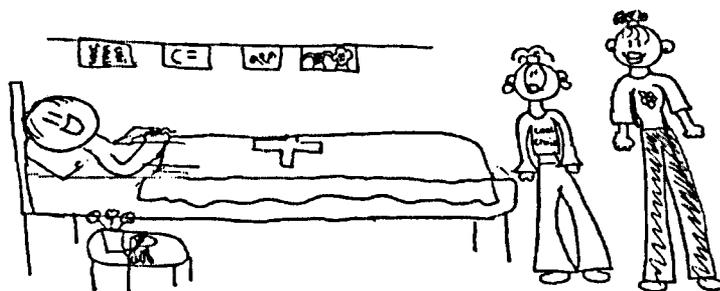
My Mum goes to the toilet.
She says "I'm not feeling well can
you give ~~me~~ me a piece of quiet."



Young people in four families spoke of staying with other people when their parent was ill. *This could be a good or a bad thing.* In one family, the children took it in turn to go and stay with their grandparents at weekends. They said it was 'nice' and 'fun'. In another family, one young person had to stay with someone she did not know very well when her Mum was in hospital. She found this upsetting.

WHAT IS IT LIKE WHEN YOUR MUM OR DAD IS IN HOSPITAL?

Twelve young people had gone to visit their parent in hospital.



Two said that they were *not bothered by it* - they knew it would make their parent better.

Others said there were *good things about visiting your parent*.

These were:

- being given sweets and crisps
- being bought things from the hospital shop
- meeting other people in the hospital who were nice
- the hospital having 'nice snugly beds'
- getting to see how your parent was, rather than sitting at home worrying about them.

There were also some things young people *did not like about hospital visits*. These were:

- it was not nice to see your Mum or Dad poorly
- it reminded them of times when they had been to hospital for treatment

HOW DO YOU FEEL ABOUT YOUR MUM OR DAD BEING UNWELL?

Young people had lots of different feelings about Mum or Dad being unwell.



Seven people said they were '*not bothered*'.

Ten said they sometimes felt '*sad*' or '*upset*'.



Eight young people mentioned being '*worried*' or '*scared*'.

Three young people spoke about '*feeling angry*'.



Two young people spoke about *feeling that their parent being ill was partly their fault*.

THINGS THAT HELP YOU FEEL BETTER

Young people were asked what helped to make them feel better if they were upset, angry or worried. The most popular suggestion was *trying to forget about it* by doing something else. The things young people did to forget about are in the box below.

THINGS THAT HELP YOU FORGET

watching television	kicking a ball about	listening to music
playing with brothers and sisters	phoning or sending text messages to friends	doing homework
reading a book	day dreaming	going to sleep

Four girls said *it helped to talk to friends*.

Two young people said *having a friend whose Mum or Dad was not very well* helped them feel less alone.

A few said *having information about Mum or Dad's health and medical treatment* was helpful.

One person said it helped *to let your feelings out* by shouting and scream.

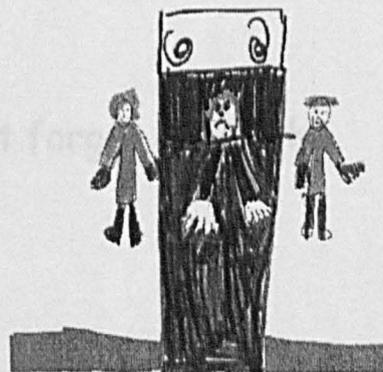
Another said it helped when her *grandparents came to visit* - they calmed her down.

A few young people spoke of *hugging cuddly toys*.

THINGS THAT HELP MUM OR DAD

Young people described all the things their Mum or Dad did that helped them feel better. They were:

- taking tablets
- sleeping, lying, or sitting down
- getting some peace and quiet
- eating or drinking the right things
- going on holiday
- taking their mind off it by working, reading, or watching television
- having homeopathic treatment
- trying to carry on with life as normal
- pushing the family to go out and enjoy themselves



mash & loto



NO! fed meat



milk



Young people also talked about *things they did to help*. They:

- helped more around the house



- made hot drinks
- tried not to bother their parent
- stayed at home to make sure Mum or Dad is all right
- tried to appear happy, even if you do not feel it



- talked about things that helped their parent forget about the illness
- gave their parent hugs and kisses
- asked how Mum or Dad was feeling
- made their parent laugh

Sometimes the *other parent helped out by:*

- persuading the ill parent to rest
- calming the parent down when in a bad mood
- going to hospital appointments with their Mum or Dad

- making drinks and meals
- doing more around the house
- giving children lifts to school

Two young people said *older brothers and sisters*, who had moved out of the house, visited regularly to check their parent was okay.

Nine people said that *family friends, aunts and uncles, grandparents, and neighbours helped out*. They looked after young people when Mum or Dad was ill, came to stay to help out, and took young people out when their parent was not able to manage it.

Three young people felt that *doctors helped* by providing treatment to make Mum or Dad better.

THE HELP YOUNG PEOPLE WOULD LIKE



Young people were asked if there was any help they would like because their Mum or Dad was sometimes ill. Most said their family did not need any extra help (though it would be good if their Mum or Dad's illness would go away).

Three young people wanted to meet other people their age who had a parent with illness like their Mum or Dad. **But** nine people said they would prefer not to meet other young people.

Four people said they would like more information and advice about their parent's health. **But** three young people said they really did not want any more information about their parent's health.

Other ideas were:

- some way of Mum or Dad getting out of the house more often
- for the house to be clean all the time so parents did not do too much housework and make themselves ill.

MESSAGES TO OTHER YOUNG PEOPLE

Some people had a message they wanted to pass on to other young people who have a Mum or Dad who sometimes gets ill. These are written below.

Don't blame yourself, don't take it out on anyone, don't get angry, anger won't solve it. Try and be supportive, and help whoever has got it.

James

Try to ignore it. She will not die, she will get better soon.

Vicky

You should feel sorry for your Mum or Dad. You could get some flowers or something to cheer them

up.

Rosie

Just not to worry because there are plenty of people whose job it is to help.

Jack

Try to be good and helpful

Grace

Don't worry about it.

Luke

I can't think of anything apart from accepting it and not taking the Mick. Probably best not to tell your friends cause when you're younger people don't really understand.

Dave

Try to help in whatever way you can. It makes you feel really bad when you know you can't help, but it makes you feel that little bit better when you try to help.

Sid

If your Mum is not feeling well please help. Then your family will be kind.

Sweet Pea

Don't worry cause there's no point

Anna

I'd say be as happy as much as you can and help out at home if your parents are ill. If your parents have only just become ill, you've got to ask questions if you don't know what's happening. And just keep happy, then everybody around you will be happy and the whole place will be happy. Keep confident, just try to be yourself as much as possible. If things are getting you down, try to be happy but don't bottle up your feelings, tell somebody.

Sam

Just look after the person who has got it. Just let them do what they want, as long as you have got good toilet facilities, that's it.

Shaggy

Don't go into the bathroom. It will probably smell !

Abigail

Appendix 49

Report on Study 2 for young people aged 11-20 years

**WHEN MUM OR DAD
FEELS ILL**

REPORT FOR YOUNG PEOPLE

**Suzanne Mukherjee,
Department of Health Sciences, University of York,
January 2002**

INTRODUCTION

This report is about what life is like for children and young people when they have a Mum or Dad who is unwell some of the time. This is because they have an illness that gives them an upset stomach and makes them have to go to the toilet a lot. It is based on a project carried out in 2001. Twenty-three children and young people, from 15 different families, took part by talking to a researcher about:

- ❖ Themselves
- ❖ Their family
- ❖ Mum or Dad and what happens when she or he is not well
- ❖ Things that help when their Mum or Dad is not well
- ❖ Messages for other children and young people

They also drew pictures, diagrams and graphs. Some of these drawings are included in this report. Most people met with the researcher in their home on one occasion between April and June 2001.

When researchers write reports they often do not use people's real names. This way everything is kept private. The young people who took part in this project were asked if they would like to make up a code name for themselves. Most people did think of a code name, or asked the researcher to think of a code name for them. A few people wanted their real name to be used. These names are:

<i>Abigail</i>	<i>Dave</i>	<i>James 1</i>	<i>Sam</i>	<i>Sweet Pea</i>
<i>Anna</i>	<i>Ginger</i>	<i>James 2</i>	<i>Sarah</i>	<i>Victoria</i>
<i>Becky</i>	<i>Grace</i>	<i>Lucy</i>	<i>Shaggy</i>	<i>Vicky</i>
<i>Charles</i>	<i>Hanna</i>	<i>Luke</i>	<i>Sid Salmon</i>	
<i>Claire</i>	<i>Jack</i>	<i>Rosie</i>	<i>Stephanie</i>	

If you took part in the project, hopefully you will recognise yourself on this list!

Three people were *advisors* to the project. They helped the researcher:

- check that the questions she was asking young people were easy to understand
- think of ways of making the project fun to take part in
- write information leaflets about the project

The advisors' code names were Gary Moor, N8 and Y2K

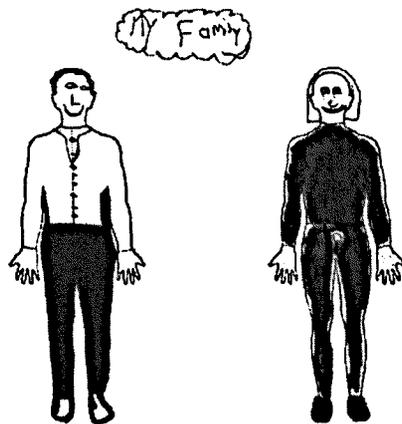
One young person took part in the project *and* was an advisor. Her code name was Sweet Pea.

Thank you to all the young people who participated in the project. Without their help, this report could not have been written.

Suzanne Mukherjee

YOUNG PEOPLE WHO TOOK PART IN THE PROJECT

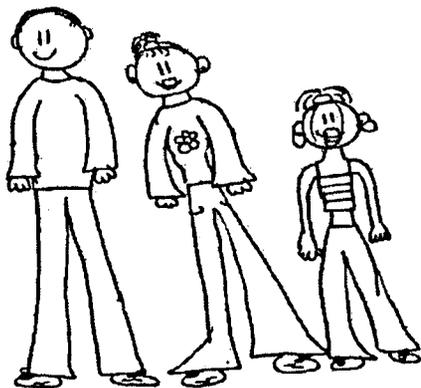
The young people who took part in the project were aged between six and twenty years. Fourteen were female and nine male. Most lived with their Mum and Dad, but five people lived with their Mum and step-Dad, two with their Mum, and one with their Dad.



Eighteen people had a brother or sister living at home.

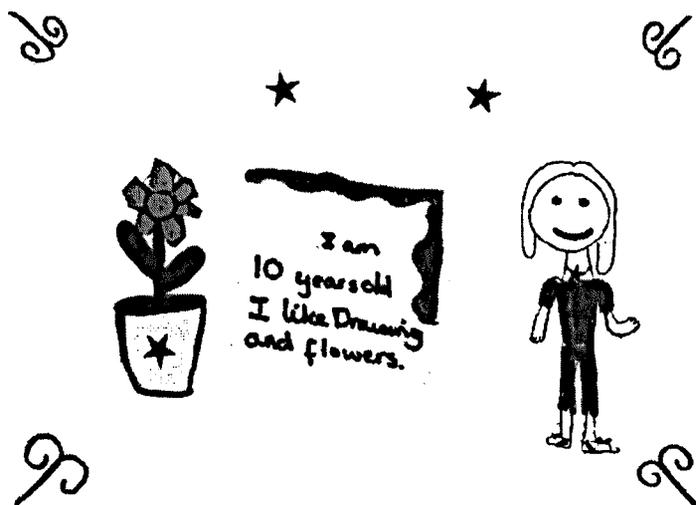


Five young people did not have a brother or sister.



In their spare time, most people enjoyed doing things at home or near where they lived. They talked about listening to music, computer games, going out on

their bike, playing with their brother or sister, playing on scooters, playing in the garden, watching television, drawing, sunbathing, and playing their guitar or piano.



They also liked lots of different sports - skateboarding, football, snooker, volleyball, table tennis, tennis, body boarding, golf, fishing, cricket, and swimming.



Two young people were members of a group or club (drama club and army cadets). Another helped out with Cubs. Three people had part time jobs. These included: working in a cafe; having a paper round; and being a DJ at youth clubs.

Almost everyone mentioned meeting up with friends. Young people also spent some of their spare time doing things with their Mum, Dad, brothers and

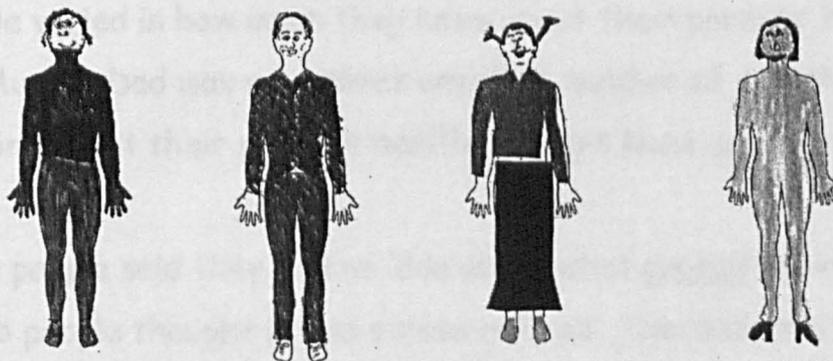
sisters. In the box below are the things people said they did at weekends and during holidays.

FAMILY ACTIVITIES

Shopping	Going 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	

Some people also spent time with other relatives - cousins, grandparents, aunties and uncles. Teenagers said they did not do as much with their family now as when they were younger, and sometimes they tried to get out of going to family events.

WHAT IS YOUR MUM OR DAD LIKE?



Everyone was asked to describe their Mum or Dad (the one who was sometimes unwell). Most people talked about their Mum or Dad's personality. Often they said their parent was 'nice' or 'kind'. Other things people said were that their parent was 'thoughtful', 'generous', 'brilliant', 'fun', 'caring', 'hard working' and 'lovely'.

Seven people talked about what a good parent their Mum or Dad was.

Sometimes this was because of all the things their Mum or Dad did for them,

like giving them lifts to places, cooking and cleaning. Others spoke about how their parent was always there for them, loving, and caring, or helped them if they were feeling down or bored. Four young people talked about how well they got on with their Mum, saying things like 'My Mum is my friend' and 'I love my Mum'. One young person was not very close to his parent when he was young, but they had grown closer as he had got older. Some people said their parent was not very strict.

Finally, a few people mentioned things they did not like about their parent.

These were:

- being made to tidy their room
- having to ring to say where you are when out with friends
- when a parent does not stand up for him/herself.
- when a parent teases you
- when a parent gets cross and bad tempered.

WHAT YOUNG PEOPLE KNEW ABOUT THEIR MUM OR DAD'S ILLNESS

Young people varied in how much they knew about their parents' health and why their Mum or Dad was sometimes unwell. A number of said they did not know anything about their parent's health. Others knew quite a bit.

Most young people said they had no idea about what caused their parent's illness. Two people thought it was stress-related. One believed it was because her parent had lots of operations. Another said when she was younger she thought it was caused by her Mum not being allowed to have babies. Now she was older she knew this was not true.

Young people found out about their parent's illness in different ways. Sometimes a Mum or Dad suddenly became ill, so they noticed their parent going to the toilet more, complaining of stomach pains, and visiting the doctor. A few parents explained what was happening.

Many young people said their Mum or Dad had been unwell for as far back as they could remember. Then they 'just knew' their parent was not very well. When they were younger, they noticed their parent was too tired to play with them or could not do the same things as other parents. Sometimes people found out about things by listening to their Mum and Dad's conversations.

IS IT SERIOUS OR NOT?

Young people had different views on how serious they felt their parent's illness was. Four young people said it was *not at all serious*. Mostly this was because their Mum or Dad was not ill very often.

Five young people thought that their parent's illness was *serious*.

Reasons for this were:

- Mum or Dad could have been very ill, but they were lucky to get treatment quickly
- being ill was very disruptive to every day life
- because Mum or Dad might have to go into hospital
- some people worried that their Mum or Dad might die.

Other young people felt the illness was *both serious and not serious*. This was because they knew their parent would *not* die from the illness, but it did get in the way of every day life.

TALKING TO OTHER PEOPLE

Some parents never talked to their children about what was happening. Others told them everything that happened. Five young people said they preferred *not to talk* to their Mum or Dad about their health. The reasons were:

- it is embarrassing
- it might be upsetting
- they did not want their parent to find out they were upset about it
- they did not think their parents wanted to talk about it

People also had different views on whether you should talk to friends. Four girls said they spoke to friends when they were upset or worried about their parent. However, another six people avoided talking to friends. Sometimes this was because their parent was usually well, so there was no need to talk to them. Others said their friends would not understand, or they worried that friends would make fun of them.

WHAT HAPPENS WHEN MUM OR DAD IS NOT WELL?

Six young people felt that their parent's health *made no difference* to their everyday life.

Three young people were able to think of *good things that happened* when their Mum or Dad was ill. These were:

- their parent would read to them when ill in bed
- very occasionally you were allowed to make your own dinner
- people in the family had become closer

Young people also talked about *things that were not so good* about their Mum or Dad being unwell. These were:

- not going out as much with your family
- sometimes the family goes out for the day, or on holiday, but Mum or Dad has to stay at home
- not going out as much with friends
- things don't get done around the house
- you have to be quiet and well-behaved
- Mum or Dad does not talk as much
- people get cross and bad tempered
- having to wait around in hospitals

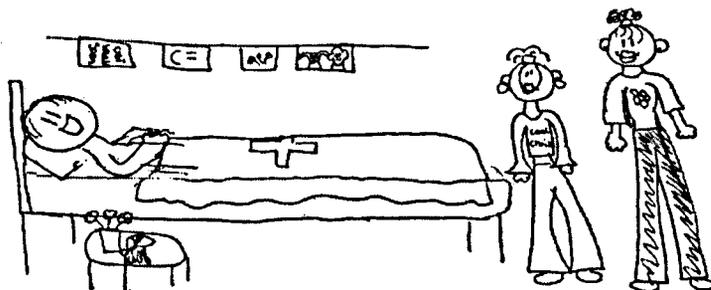
My Mum goes to the toilet.
She says "I'm not feeling well can
you give ~~me~~ me a piece & quiet."



Young people in four families spoke of staying with other people when their parent was ill. *This could be a good or a bad thing.* In one family, the children took it in turn to go and stay with their grandparents at weekends. They said it was 'nice' and 'fun'. In another family, one young person had to stay with someone she did not know very well when her Mum was in hospital. She found this upsetting.

WHAT IS IT LIKE WHEN YOUR MUM OR DAD IS IN HOSPITAL?

Twelve young people talked about visiting their parent in hospital. Other young people had not visited their parent, or their parent had never had to stay in hospital overnight.



Young people had very different views on visiting their parent in hospital. Two said that they were *not bothered by it* - they knew it would make their parent better.

A number of young people said there were *good things about visiting your parent*. These were:

- being given sweets and crisps
- being bought things from the hospital shop
- meeting other people in the hospital who were nice
- the hospital having 'nice snugly beds'
- getting to see how your parent was, rather than sitting at home worrying about them.

Three young people *did not like hospital visits*. This was because:

- it was not nice to see your Mum or Dad poorly
- it reminded them of times when they had been to hospital for treatment

Other people said there were *both good and bad things about hospital visits*.

For example, it was not nice seeing someone in hospital, but that you knew they would get better.

People also talked about what happens at home when Mum or Dad is in hospital. A few said it was strange not having their 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 person liked being allowed to stay up late and sleep in her parents' double bed when her father was in hospital.

HOW DO YOU FEEL ABOUT YOUR MUM OR DAD BEING UNWELL?



Young people had lots of different feelings about Mum or Dad being unwell. Seven people said they were '*not bothered*'.

Usually this was because their parent was not ill very often.

Also, some people noticed their parent getting better after having treatment. One young person, whose parent spent a lot of time in hospital, said she was used to him being in hospital so it did not bother her.

Ten young people spoke of feeling '*sad*' or '*upset*' about their parent being unwell.



They gave lots of reasons for this:

- it was not nice seeing your parent poorly
- it was not nice finding out for the first time that your parent was unwell
- they thought their parent would not return home from the hospital
- they thought their parent might die.
- their parent had not been able to go out or on holidays with the family

Eight young people mentioned being '*worried*' or '*scared*'.

Reasons for feeling worried or scared were:

- being confused about what Mum or Dad was well enough to manage
- thinking about what might happen during an operation
- thinking that Mum or Dad might die
- not wanting to visit their parent in hospital
- thinking that they might get the same illness



Three young people spoke about '*feeling angry*'. The reasons they gave for feeling angry were:

- thinking about what it would be like if their parent died
- having to stay indoors to keep their parent company
- not being allowed to eat certain foods because Mum or Dad could not
- thinking that Mum or Dad should be offered better treatment by doctors
- being annoyed that tablets were left lying around the house
- being annoyed that Mum or Dad did not take medication regularly - sometimes they forgot and sometimes they took too many tablets

Two young people spoke about *feeling that their parent being ill was partly their fault*. One person thought his parent's condition might be stress-related, so he might be partly to blame for his parent becoming ill. Another talked about a time when her parent became unwell after taking her out for the day.

THINGS THAT HELP YOU FEEL BETTER

Young people were asked what helped to make them feel better if they were upset, angry or worried. A few said there really was nothing they could do since they could not alter the fact that their parent was ill. Other people had suggestions.

The most popular suggestion was *trying to forget about it* by doing something else. The things young people did to forget about are in the box below.

THINGS THAT HELP YOU FORGET		
Watching television	kicking a ball about	listening to music
playing with brothers and sisters	phoning or sending text messages to friends	doing homework
reading a book	day dreaming	going to sleep

Four girls said *it helped to talk to friends*.

Two young people said *having a friend whose Mum or Dad was not very well* helped them feel less alone.

A few said *having information about Mum or Dad's health* and medical treatment was helpful.

One person said it helped *to let your feelings out* by shouting and scream.

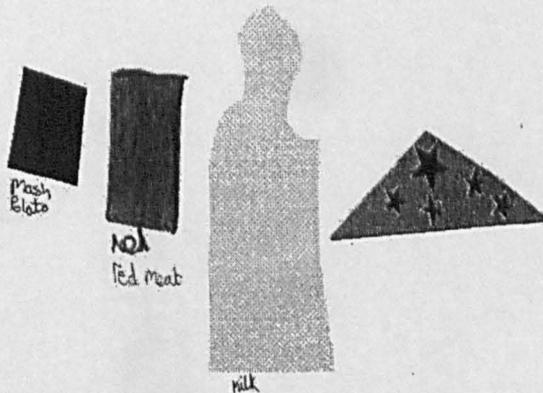
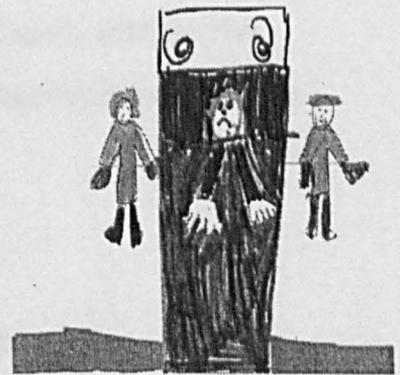
Another said it helped when her *grandparents came to visit* - they calmed her down.

A few young people spoke of *hugging cuddly toys*.

THINGS THAT HELP MUM OR DAD

Young people described all the things their Mum or Dad did that helped them feel better. They were:

- taking tablets
- sleeping, lying, or sitting down
- getting some peace and quiet
- eating or drinking the right things
- going on holiday
- taking their mind off it by working, reading, or watching television
- having homeopathic treatment
- trying to carry on with life as normal
- pushing the family to go out and enjoy themselves



Young people also talked about *things they did to help*. The most popular way of helping was to do more around the house. Eleven young people mentioned doing this, but most said it was 'no big deal'. They mostly did things

that were not too much trouble to do, like washing up dishes, setting the table, making snacks, making hot drinks and heating up food in the microwave.



One young person felt he did a lot around the house, but said this was the case whether or not his parent was ill.

Seven young people spoke about not bothering their parent when ill. This included staying out of the way, giving him/her peace and quiet, letting the parent watch what they wanted on television, and not bothering him/her with talking about things that had happened during your day.

Other ways of helping were:

- staying at home to make sure Mum or Dad is all right
- trying to appear happy, even if you do not feel it



- talking about things that take your parent's mind off the illness
- giving your parent hugs and kisses

- asking how Mum or Dad is feeling
- making the parent laugh

Twelve young people spoke about how their *other parent helped out*. This included:

- persuading the ill parent to rest
- calming the parent down when in a bad mood
- going to hospital appointments with their Mum or Dad
- making drinks and meals
- doing more around the house
- giving children lifts to school

Two young people said *older brothers and sisters*, who had moved out of the house, visited regularly to check their parent was okay.

Nine people said that *family friends, aunts and uncles, grandparents, and neighbours helped out*. They looked after young people when Mum or Dad was ill, came to stay to help out, and took young people out when their parent was not able to manage it.

Three young people felt that *doctors helped* by providing treatment to make Mum or Dad better. One person was grateful to *social services* for putting an extra toilet in the house, and providing a special adapted car and disabled parking spaces, to make it easier for the parent to go out.

THE HELP YOUNG PEOPLE WOULD LIKE



Young people were asked if there was any help they would like for themselves or their family because their Mum or Dad was sometimes unwell. Most people said their family were managing well on their own and did not need any extra help (though it would be good if their Mum or Dad's illness would go away).

Three young people wanted to meet other young people their age who had a parent with illness like their Mum or Dad. But nine people said they would prefer not to meet other young people.

Four people said they would like more information and advice about their parent's health. They wanted:

- general information on the condition
- to be told about what was happening to their parent
- advice on how to behave around their parent

One person suggested there should be a health professional specifically for families to talk to. But three young people said they really did not want any more information about their parent's health.

Other suggestions were:

- some way of Mum or Dad getting out of the house more often
- for the house to be clean all the time so parents did not do too much housework and make themselves ill.

MESSAGES TO OTHER YOUNG PEOPLE

Some people had a message they wanted to pass on to other young people who have a Mum or Dad who sometimes gets ill. These are written below.

Don't blame yourself, don't take it out on anyone, don't get angry, anger won't solve it. Try and be supportive, and help whoever has got it.

James

Try to ignore it. She will not die, she will get better soon.

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You should feel sorry for your Mum or Dad. You could get some flowers or something to cheer them up.

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Just look after the person who has got it. Just let them do what they want, as long as you have got good toilet facilities, that's it.

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