

**Parental coping with Paediatric Encephalitic Brain Injury**

**Thesis submitted for the degree of  
Doctorate in Clinical Psychology for the  
University of Leicester**

**Stephen Bainbridge**

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## **Declaration**

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for any other degree, or to any other institution.**

# **Parental coping with Paediatric Encephalitic Brain Injury**

**Stephen Bainbridge**

## **ABSTRACT**

### **Section One**

The literature on encephalitis including its aetiology, prevalence and neuropsychological impact on paediatrics is outlined. This leads on to a critical review of the current literature detailing how parents cope with the impact of paediatric brain injury and chronic illness in children. The need for further qualitative studies examining parental coping with paediatric brain injury is highlighted, along with a call for including the experiences of fathers.

### **Section Two**

This study set out to examine how parents cope with their children's encephalitic acquired brain injury, and whether any differences in coping exist between mothers and fathers.

Semi-structured interviews were conducted with five parents who volunteered through the Encephalitis Society to take part in the study: two spousal couples and a single mother. Interviews were transcribed verbatim and analysed according to the grounded theory method (Charmaz, 2003). Main categories were generated from the analysis and a core category was identified entitled 'Thinking Positively'. A process model of coping was developed. All parents appeared adjusted and were coping when the interviews were conducted. Data analysis revealed gender differences: mothers were seen to be taking on more coping demands and engaging in more problem-solving activities related to their child's brain injury than did the fathers.

A consideration of the constraints in interpreting the current findings on the basis of (N = 5) is made. Implications for NHS and clinical psychology services in understanding how parents cope are outlined, and ideas for future research suggested.

### **Section Three**

The critical appraisal chronicles the researcher's reflections on the research process. Learning points are outlined and ideas for disseminating research findings suggested.

## **Acknowledgements**

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### Section 3.

Critical Appraisal	3, 912 (References 220)
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<b>Total</b> (excluding references and appendices)	25097 words
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(with references and appendices)	31989 words
----------------------------------	-------------

## **Contents**

<b>Contents</b>	<b>Page</b>
<b>List of Appendices</b>	<b>x</b>
<b>List of Figures</b>	<b>xi</b>

## **Section 1. Review Article**

### **Title: Paediatric Viral Encephalitic Brain Injury: How Parents Cope with Chronic Illness in Children.**

<b>1.1</b>	<b>Abstract</b>	<b>1</b>
<b>2.0</b>	<b>The Nature of Encephalitis</b>	<b>2</b>
<b>3.0</b>	<b>Aim and Search Strategy</b>	<b>7</b>
<b>4.0</b>	<b>The Impact of Paediatric Acquired Brain Injury and Chronic Illness on Parents' Social, Psychological and Family Morbidity</b>	<b>9</b>
<b>5.0</b>	<b>Theoretical Conceptualisations and Dimensions of Coping</b>	<b>15</b>
<b>6.0</b>	<b>Summary</b>	<b>22</b>
<b>7.0</b>	<b>Parental Coping with Paediatric Chronic Illness</b>	<b>23</b>
<b>8.0</b>	<b>Summary</b>	<b>33</b>
<b>9.0</b>	<b>Conclusion and Future Research</b>	<b>34</b>
<b>10.0</b>	<b>References</b>	<b>36</b>

## **Section 2. Research Report**

<b>Abstract</b>	<b>49</b>
<b>1.0. Introduction to the current study</b>	<b>50</b>
1.1. Encephalitic Acquired Brain Injury	50
1.2. Systemic Impact of Paediatric Acquired Brain Injury on Families	52
1.3. Coping Literature	52
1.4. Qualitative Studies on Parental Coping with Paediatric Brain Injury	53
1.5. The Need to include Fathers	54
1.6. The Clinical and Policy Context	55
1.6.1. Implications for NHS Clinical Psychology Services and CAMHS	56
1.7. Understanding Parenting Stress	56
1.8. The Current Study	57
1.9. Research Aims	59
<b>2.0 Method</b>	<b>60</b>
2.1 Recruitment	60
2.2. Participants	61
2.2.1 Parents	61
2.2.2. Child Demographics	62
2.3. Data Collection	63
2.4. Grounded Theory as a Qualitative Method	65
2.5 Rationale for using Grounded Theory	65



2.6.	Procedure: Data Analysis	66
2.6.1	Line-by-Line Coding	66
2.6.2	Focused Coding	67
2.6.3.	Category Development	67
2.6.4.	Memo-Writing	68
2.7.	Theoretical Sampling	68
2.8.	The Position of the Researcher	69
2.9	Reflexivity	70
3.0	Summary: The Methodological Aim	70
<b>4.0</b>	<b>Analysis</b>	<b>71</b>
4.1	Overview	71
4.2	The Process Model	71
4.3	The Core Category: Thinking Positively	74
4.4	Main Category: Maintaining Togetherness	78
4.4.1.	Intermediate-level category: Family Support	81
4.4.2.	Intermediate-level category: External Professional Support	84
4.4.3.	Intermediate-level category: Therapeutic Break	86
4.5.	Main category: Allocating Labour	88
4.5.1.	Intermediate-level category: Working Together	90
4.5.2.	Intermediate-level category: Specialising	92
4.5.3	Intermediate-level category: Segregation	94
4.6.	Main Category: Learning	95
4.6.1.	Intermediate-level category: Active Learning	97
4.7.	Main Category: Finding a Solution	102

4.7.1. Intermediate-level category: Prioritising	104
4.7.2. Intermediate-level category: Problem-Solving	105
4.7.3. Intermediate-level category: Fighting	107
4.7.4. Intermediate-level category: Recognising own Needs	109
<b>5.0 Discussion</b>	<b>111</b>
5.1. Interpretation of the Model	111
5.2. How do parents cope with paediatric encephalitic brain injury?	112
5.3. Are there any gender differences in coping?	113
5.4. Clinical implications	116
5.5. Limitations of the study	119
5.6. Ideas for future research	120
<b>6.0. Conclusion</b>	<b>121</b>
<b>7.0. References</b>	<b>123</b>

## **Section 3. Critical Appraisal**

<b>1.0. Critical Appraisal</b>	<b>134</b>
1.1. Planning the research	134
1.2. Choosing qualitative research	136
1.3. Epistemological stance of the researcher	137
1.4. Conducting the research	138
1.5. Analysis and Write-up	143
1.6. Enhancing Methodological Rigour	144
1.7. Reflexivity	145
1.8. Dissemination of findings	146
1.9. Learning outcomes	146
<b>2.0. References</b>	<b>149</b>

<b>Appendices</b>	<b>151</b>
-------------------	------------

Appendix 1. Invitational letter from the Encephalitis Society	152
Appendix 2. Invitational letter from the Principal Researcher	153
Appendix 3. Participant Information Sheet	154
Appendix 4. Letter of ethical approval from LREC	155
Appendix 5. Letter of ethical approval from the Encephalitis Society	156
Appendix 6. Interview Schedule	157
Appendix 7. Participant consent form	158

Appendix 8. Coding extract	159
----------------------------	-----

## **List of Figures**

Box 1.	Extract from Principal Researcher's Journal	70
Figure 1.	The core category and the process model	73
Figure 2.	Maintaining Togetherness	79
Figure 3.	Allocating Labour	89
Figure 4.	Learning	96
Figure 5.	Finding a Solution	103

## **Section 1**

### **Review Article**

#### **Paediatric Viral Encephalitic Brain Injury: How Parents Cope with Chronic Illness in Children**

## **REVIEW ARTICLE**

### **Paediatric Viral Encephalitic Brain Injury: How Parents Cope with Chronic Illness in Children**

**Stephen Bainbridge**

#### **1.1 Abstract**

Encephalitis is a rare complication of any viral infection that results in acquired brain injury for a small number of children in the U.K each year.

The goal of this review is to present a descriptive account of viral encephalitis, before embedding it within a critical overview of a wider empirical literature on parental coping.

Paediatric parenting stress is discussed in the light of findings of research into the impact of childhood acquired brain injury on parents' social, psychological and family morbidity. Theoretical and conceptual dimensions of coping are outlined in the context of contrasting literature. Research examining gender differences in the coping process is highlighted and the results are reviewed in the context of an understanding of their methodological properties. Recent studies of parental coping with paediatric acquired brain injury are discussed in order to enhance understanding of the factors mediating adjustment.

There is a summary highlighting the inconclusiveness of much of the reviewed literature. Existing gaps in theoretical understanding are elucidated and ideas are suggested for future research. To this aim, qualitative research techniques are advocated and briefly justified in the light of eliciting a depth of understanding not currently known about coping with paediatric encephalitic brain injury.

*Keywords: encephalitis, paediatric, acquired brain injury, parents, coping, qualitative*

## **2.0. The Nature of Encephalitis**

ENCEPHALITIS is an acute inflammatory process that affects the brain parenchyma (Denizmen *et al.* 2001) and the central nervous system (CNS). It is a rare complication of any viral infection and a medical emergency. Several different microbes are known to cause sporadic encephalitis, including bacteria, fungi, parasites and common childhood viruses such as measles, mumps and rubella. Between 0.5 and 2 per cent of patients with mumps develop an encephalitic illness (Hokkanen & Launes., 2000). Herpes simplex virus is the most common single aetiology associated with encephalitis (Davison *et al.* 2003) and more likely to cause severe symptoms. In contrast, bacterial encephalitis can be easily treated with antibiotics and rarely causes long-term neurological damage.

Children with an acute onset of viral encephalitis, developing within hours or a few days, typically experience symptoms of fever, malaise, headache, gastro-intestinal disturbance and upper respiratory infection (Illis & Gostling, 1972). This can give rise to confusion and delirium leading to a stupor and progressive decline in consciousness. Seizures and aphasia are also commonly observed (Boose & Esiri, 1986).

Clinical diagnosis of viral encephalitis is based on observation of neurological symptomology, although a definitive diagnosis involves detecting the virus in the cerebrospinal fluid or brain by biopsy, lumbar puncture and brain imaging (Denizmen *et al.* 2001). In clinical practice, the specified causative agent of encephalitis is seldom

established in between 30% and 60% of cases (Hokkanen & Launes., 2000) as the use of virologic investigation has been inconsistent in England (Davison *et al.* 2003).

In many cases, children who have been ill with encephalitis are likely to incur varying degrees of damage to nerve cells often resulting in acquired brain injury (ABI) (Steiner *et al.* 2005). The extent of permanent brain damage depends on the localisation of brain tissue affected, the immunological state of the host and the age at which the illness occurred; the long-term effects of encephalitis can therefore vary considerably between individual children. The child's age, ability, culture, injury severity, family and personality before the illness are all important-factors in determining recovery outcome following encephalitis (Ylvisaker, 1998).

### **2.1. Herpes Simplex Virus Encephalitis (HSVE)**

In the western world, sporadic viral infections account for the majority of encephalitis cases (Wood & Anderson, 1988). The virus is known to remain latent primarily in the trigeminal ganglia area of the brain, and, once activated, to result in the typical labial lesion known as the cold sore. At times, the virus spreads via the trigeminal nerve up to the brain (Davis & Johnson, 1979; cited in Denizmen *et al.*, 2001) where it can cause various central nervous system (CNS) infections. Focal necrosis in the medial temporal lobes, hippocampal complex, and the basal forebrain can typically occur (Kapur *et al.* 1994).



The different modes of presentation documented in the literature indicate common signs of HSV including early psychological or personality changes, seizures, fever, headaches, drowsiness and aphasia (Whitley *et al.* 1982). Drachman and Adams (1962) observed the presence of peculiar or challenging behaviour, labile affect, memory disturbance, and hallucinations.

Without treatment, herpes simplex encephalitis has up to a 75% mortality rate (Huber *et al.* 1989) with severe disability and dependency in survivors. The number of deaths drops to 15% to 20% with treatment by antiviral drugs such as Acyclovir (Zovirax). The specific antiviral treatment for herpes simplex encephalitis is not effective against other families of viruses, therefore the specific causative agent must be found prior to treatment with antiviral medication with selective effectiveness (Booss & Esiri, 1986).

## **2.2. Other Viruses that cause Encephalitis**

Encephalitis can occur as a secondary consequence of common childhood viruses including the varicella-zoster virus which is responsible for chickenpox, the measles virus, rubella virus and the Epstein-Barr virus. In all these cases, encephalitis may be due to hypersensitivity – an overreaction of the immune system to a foreign substance (Illis & Gostling, 1972). Arboviruses can also result in encephalitis and are transmitted by mosquitoes and ticks. This is the most common cause of epidemic encephalitis and is frequent in certain parts of the world, although only a few rare, and imported cases, have been reported in the U.K. (Davison *et al.* 2003).

### **2.3. Neuropsychological Consequences of Encephalitis**

Young children with acquired brain injuries typically have a poorer functional prognosis and more global impairments than adolescents and adults (Rutter, 1982). Previously learnt skills and information are often preserved in middle childhood, although in younger children fewer skills have been developed and brain damage may chronically impede future development (Tselis & Booss, 2003).

Viral encephalitis can cause mild to severe brain damage and result in long-term problems with thinking, memory, behaviour and emotional functioning (Taylor & Stancin, 2003). Higher-order or executive skills such as reasoning, planning and self-regulation can also be affected. Personality changes may result from encephalitis or as a secondary consequence of damage to cognitive functions. Research has indicated that anterograde memory deficits are extremely common following herpes simplex virus encephalitis (Kapur *et al.* 1994). The virus affects the medial temporal lobes and its structures; the hippocampus and the amygdala (Tranel & Damasio, 1995). Such damage can make the learning of new knowledge and facts extremely difficult.

Dysphasia is also a common consequence of damage to the frontal-temporal cortex, usually characterised by difficulties in all categorical naming tasks, and less commonly in deficits in receptive speech. Furthermore, psychiatric and behavioural symptoms often precede, accompany, and follow acute encephalitis (Schlitt *et al.* 1985). These can include panic and anxiety disorders, aggressive outbursts, challenging

behaviour and depression. Increased oral exploratory behaviour, loss or diminished control of anger responses and sexually disinhibited behaviour have all been observed in post-encephalitic patients (Booss & Esire, 1986). According to Hokkanen and Launes (2000) the presence of psychiatric symptoms can be explained as an emotional reaction to having experienced a fatal illness or, alternatively, by damage to the limbic system and amygdalo-frontal pathways caused by encephalitis.

#### **2.4. Epidemiology of Viral Encephalitis in England**

Epidemiology has an instrumental role to play in revealing patterns in the occurrence of disease and determining risk factors and aetiology, thus guiding service planning and delivery of head injury services (Cockerell *et al.* 1993; cited in Davison *et al.* 2003). This is all the more important given that information on the rate of occurrence of neurological disorders in the community is lacking (Newsom-Davis & Hopkins, 1997).

Davison *et al.* (2003) investigated the number of people with encephalitis being admitted to hospital in England. They found that between April 1 1989 and March 1998, a total of 6,414 adults and children were hospitalised with a diagnosis of viral encephalitis. This corresponds to approximately 700 cases each year (46 fatal) or an estimated annual rate of 1.5 cases per 100,000 population. A specific diagnosis was recorded for 2,574 patients, of whom 52% had herpes simplex encephalitis; most of the other patients had a non-specific infection.

A total of 2,734 cases were children, which included 35 in neonates - corresponding to an estimated annual rate of 2.8 per 100,000 children and accounting for 43% of all hospitalisations with viral encephalitis. Over half (51%) of hospitalizations occurred for those under the age of five with the highest rate of 8.7 per 100,000 for infants under one year of age. This remained the highest rate throughout the duration of the study. Such statistics clearly illustrate that a diagnosis of encephalitis in infancy may result for the majority of children in their neural and maturational development being interrupted or permanently disrupted. This can have far-reaching ramifications for the child, its parents and rehabilitation services that all have to cope with the sometimes chronic sequelae of viral encephalitis.

### **3.0. Aim and Search Strategy**

The aim of this review was to examine how parents cope with their child's acquired encephalitic brain injury. This is a highly selective review and by no means exhaustive. Articles were chosen which afforded evidence for the theoretical supposition that acquired brain injury resulting in chronic illness creates 'paediatric parenting stress' (Streisand *et al.* 2001) which is mediated by parental coping strategies. The term paediatric refers to the development and care of infants, children and adolescence with some type of illness (Hoghughi & Long, 2004).

Between September 2003 and January 2005, three comprehensive searches of Medline (National Library of Medicine), PsychINFO, AMED (Allied Complementary Medicine)

Ovid, BioMed and SwetsWise databases were undertaken for relevant literature between 1970 and 2005. Review articles and book chapters were also included. A search using the traditional 'snowball' method was adopted. Search strategies used the following key text words: 'encephalitis', 'chronic neurological illness in children', 'childhood acquired brain injury', 'coping', 'parental coping and stress' and 'gender differences in coping'.

A wide spectrum of literature was generated from the initial search. Successive searches were repeatedly narrowed by combining phrases together such as 'parental coping' and 'childhood chronic illness' or 'coping' and 'childhood brain injury'. Results indicated a very small body of research on parental coping with paediatric brain injury, and none related specifically to encephalitic brain injury. The selected material for review is therefore what the researcher regards as the most relevant and representative for the present state of research.

Studies which explicitly focus on parental coping with paediatric acquired brain injury are relatively small in number compared to literature on adult brain injury or other chronic health conditions in children. No research has examined parental coping with paediatric brain injury caused specifically by viral encephalitis. Given this lack of empirical and theoretical research, it may be useful to draw on a broader literature. Research on parental coping with chronic illness in children may therefore provide a meaningful framework in which to better understand the relatively ignored area of encephalitic brain injury.

#### **4.0. The Impact of Paediatric Acquired Brain Injury and Chronic Illness on Parents' Social, Psychological and Family Morbidity**

##### **4.1. Effects on Family**

The majority of children and their parents adapt and cope effectively with chronic illness (Tansella, 1995; Krauss, 1990). However, evidence demonstrates that families affected by paediatric illness are at an increased risk of showing maladjustment and poorer mental health states compared to families with healthy children (Wallander & Varni, 1995).

##### **4.2 Parental Stress**

Sokol *et al.* (1995) examined behavioural adjustment and parental stress in 25 caregivers of children with closed head injury. The results indicated that nearly one-half (44%) of the parents scored within the 'significantly distressed' range on a questionnaire measuring the caregiver's sense of competence, relationship with spouse, depression, health and attachment to the injured child. Only 20% would be expected to show similar levels of stress in the general population. The sample also attributed the cause of their stress to having to deal with disturbances in the child's behaviour, as opposed to personal factors, such as relationship with spouse or attachment to their child.

##### **4.3. Mothers and Fathers**

Psychological sequelae usually emerge in parents at the time the child's illness is

diagnosed, and may continue to affect family life for years thereafter (Hoghughi & Long, 2004). Several studies of parents of chronically sick children have shown that mothers in particular are more likely than fathers to suffer from increased levels of stress, anxiety and depression (Kazak & Marvin, 1984; Sloper & Turner, 1991); other studies have not (Kazak & Meadows, 1989; Spaulding & Morgan, 1986). Many studies have been based on an approach combining children with diverse medical conditions, a wide range of ages, and different phases of the illness into one sample (Stein & Jessop, 1989). Such an experimental design makes generalisation difficult and neglects important factors such as the severity and duration of the stressor, hence only weak relationships have been found between stress and psychological adaptation in parents (Wallander *et al.* 1989).

Mothers, as primary caregivers, often feel overwhelmed by the demands of caring for their child, experience more restrictions on their personal freedom, and report less satisfaction with life than mothers in control samples (Kazak & Marvin, 1984). Social support networks in families with chronically ill children are small, denser and qualitatively different from those of healthy families (Tansella, 1995). Typically, parents report having less time to spend in social and recreational activities (Quittner *et al.* 1992). Studies have indicated that fathers experience greater stress in relation to finances and emotional attachment to the child, whereas mothers have reported greater stress in managing daily activities and medical regimens (Quittner *et al.* 1992; Shonkoff *et al.* 1992). Elevated levels of stress among parents may also result in stress consequently experienced by children confronting health risks (Johnson & Tercyak, 1995): possibly through systemic family modelling of anxiety, worry and apprehension (Hoghughi &

Long, 2004). This evidence is important as it emphasises the existence of a bi-directional relationship between children and their parents in the recovery process.

#### **4.4. Family Structure and Support**

Stress caused by paediatric brain injury may impact on family functioning in terms of disrupting existing organisational structures, as well causing difficulties in communication between immediate family members. Waaland and Raines (1991) reported their clinical observations that marital relationships tend to deteriorate and become troubled when one partner, usually the mother, assumes a disproportionate amount of the caregiving. Gottman (1993) speculated that this leads to the marital relationship being overwhelmed by maternal negative emotional affect arising from anxiety. This in turn then may result in the father becoming disengaged, which further adds to the potential for marital dissolution and family break-up. Evidence indicates that the organisational make-up of the family is also altered in response to the child's illness; the father tends to be excluded from the parent sub-system, while remaining central to the spouse sub-system (Tansella, 1995).

Many studies of parents with chronically ill children have consistently reported greater marital strain, conflict and higher rates of divorce than in groups of control parents (Tew *et al.* 1974). In recent years studies have offered contradictory evidence that these parents are no more likely to divorce than others (Quittner *et al.* 1992) in fact, certain studies have reported positive benefits in terms of increased marital cohesion and togetherness



(Holmbeck *et al.*, 1997). The different findings of these studies can be explained by the need to go beyond global measures of marital satisfaction, which are routinely administered, and instead focus specifically on sources of tension and problems with intimacy and communication which may yield more ecologically valid findings (Klennert *et al.* 1992).

#### **4.5. Family Breakdown**

Harris *et al.* (1989) found that 40% of families in their sample encountered changes in family composition following the occurrence of paediatric brain injury. Reported changes included reunification in 32% of families where parents were formerly estranged, and separation or divorce in 8% of previously cohesive families. Harris *et al.* also produced findings indicating marital tensions in 32% of families, emotional and behavioural difficulties in 46%, and financial difficulties afflicting 60% of injured children's families. A methodological weakness of these family psychosocial outcome studies is that they neglect relatives other than the primary caregiver, thus denying a broader perspective of family functioning which encompasses extended family.

Based on clinical experience of working with head trauma victims, Lezak (1988) described the psychological consequences of brain damage as an all encompassing 'family affair'; afflicting psychosocial burden on immediate family members in the long-term, and feelings of bewilderment, guilt, depression and stress in the immediate aftermath of the illness. Following content analysis of interview transcripts with parents

of children with traumatic brain injuries, a core theme in Lezak's research emerged.

Parents, during the acute stage, witnessed their hopes being dashed alongside the sudden depressing realisation that responsibility for the care and well-being of the child will terminate only with death.

Lezak described the destructive impact of childhood brain injury on family functioning by stating:

“Significant brain damage in a minor child tends to arrest the normal evolution of the family as the parents settle in to care for a perpetually dependent family member . . .” (Lezak, 1988: 121)

The clinical value of Lezak's (1988) research resided in providing an insight into the potential collapse of the family's evolutionary theme, which emphasised the relationship between neurobehavioural sequelae of brain injury and decreased cognitive efficiency on family function. Similar research has produced results which support the idea of altered family functioning (Hall *et al.* 1994; Peters *et al.* 1990). Utilizing a phenomenological approach to qualitative research, Prentiss (1998) used a synthesis of methods including interviews, observations and artefacts to gain a deeper understanding of the parental experience of acute paediatric brain injury. Themes surrounding complicated bereavement, as well as overall family disruption, ongoing stress and conflicts with others were unearthed. However, the study failed to pay equal attention to the parental

experience of fathers, thus reducing the overall scope and validity of its conclusions. Lezak's clinical experience of working with relatives was drawn primarily from her running family support groups and is probably therefore biased towards a more distressed group of families.

#### **4.6. Siblings**

In the U.K 80% of people grow up with brothers and sisters (Nodell, 1990). Polinko (1985) reported that siblings' psychological needs are very often neglected by both professionals and parents of brain-injured children; they tend to be isolated during the acute hospitalisation stage and this can continue in the longer-term. Siblings of brain-injured children often typically express feelings of jealousy, anger and disapproval of the central role played by the brain-injured child, and this leads them to withdraw their support (Orsillo *et al.*, 1993).

#### **4.7. Economic Problems**

There is evidence in the literature, albeit limited, that work and financial problems following paediatric acquired brain injury can add further strain which has an adverse impact on family functioning. Harris *et al.* (1989) studied a sample of 50 children with severe brain injury, and found that 60% of their parents reported financial difficulties with resultant social problems. They reported that 21 mothers who had been employed before their child's injury, had stopped working to care for their child, and that 20% of families had exhausted their savings and gone into debt.

Despite mixed findings, these studies indicate psychosocial morbidity to varying levels among parents, nevertheless, it has been noted that relatives of brain-injured individuals are not universally distressed (Adams, 1996; Camplair *et al.* 1990; cited in Kreutzer *et al.* 1997). An important mediating factor appears to be the extent to which parents are able to cope successfully with their child's illness.

#### **4.8. Summary**

Encephalitic acquired brain injury, along with other childhood chronic illnesses, impacts upon family structure and functioning. Studies indicate that both mothers and fathers experience stress, with mothers reporting heightened levels of psychological sequelae including depression and anxiety. Marital conflict, role tension and partnership dissolution have been identified as consequences of parenting a chronically ill child. Siblings of brain-injured children often feel excluded and experience jealousy and anger. There is some evidence, although limited, that families incur financial and work pressures following acquired brain injury, which creates further stress.

### **5.0. Theoretical Conceptualisations and Dimensions of Coping**

#### **5.1. Transactional Model of Coping**

Theoretical and conceptual definitions of coping in the literature have been influenced over the years by the continuing debate about its constituent properties. Traditionally, intra-psychic models espoused the notion of stable personality traits or static coping 'dispositions' that assist people in dealing with life strains. The emphasis was on people

using modal styles of coping that transcended role or situational boundaries (Carver *et al.*, 1989).

Lazarus and Folkman (1984) offered a cognitive behavioural, process-centred, transactional perspective viewing stress and coping as related constructs (Levy-Shiff *et al.*, 1998). This view highlights the interchange between a person's resources and the demands of events or situations on these resources.

According to the transactional perspective, coping is defined as constantly shifting cognitive and behavioural strategies that are used to manage stressors that are appraised as exceeding personal resources. The term 'manage' does not necessarily equate to mastery but also refers to minimizing, tolerating, avoiding and accepting stressful events (Lazarus & Folkman, 1984). Given that the presence of a chronic illness in a child frequently commits the family to long-term difficulties comprising a variety of stressors (Tansella, 1995), the approach emphasises the perceived controllability of a stressor. Coping mediates the effects of stress on a parent and child's emotional well-being.

## **5.2. Appraisal Processes**

Lazarus (1966) argued that stress comprises three processes pertaining to appraisal. Primary appraisal is an evaluative process aimed at perceiving whether a stressor is positive, threatening or controllable in implication. Secondary appraisal refers to the process of generating a response to the stressor. Personal and diverse environmental

factors may impinge upon the quality of a person's appraisal and affect how they emotionally, physiologically and behaviourally react (Tomaka *et al.* 1993). Coping is the process of executing a response (Carver *et al.* 1989).

### **5.3. Defining Problem-Focused Coping**

Lazarus & Folkman (1984) made a taxonomic effort to conceptualise coping strategies by distinguishing between problem-focused and emotion-focused coping. Problem-focused coping refers to strategies aimed at altering external causes of stress or ameliorating its effects. This can involve several distinct activities: planning, taking direct action, seeking assistance, prioritising activities and generating alternative solutions (Lazarus & Folkman, 1984; Carver *et al.* 1989). Problem-focused strategies are also aimed at altering internal sources of stress by cognitively restructuring and thus redefining the meaning attached to the stressor. Kahn *et al.* (1964) referred to these inward-directed strategies as cognitive reappraisals that are problem-focused.

### **5.4. Problem-Focused Coping and Social Support**

Carver *et al.* (1989) explored and assessed the diversity in coping strategies found in the theoretical literature. Within the problem-focused repertoire, 'suppressing of competing activities' was identified as a useful skill in enabling people to channel their concentration into dealing with the stressor at hand. Another tactic was seeking out social support: conceptually comprising two distinct functions. Seeking social support for instrumental reasons relates to wanting advice, assistance or information. Looking for

social support for emotional reasons such as moral guidance, empathy or understanding, constitutes an aspect of emotion-focused coping. The functionality of receiving emotional support allows people to express their insecurities and thereby fosters their return to problem-focused coping (Pearlin & Schooler, 1978).

Research highlights that positive coping behaviours coupled with social support resources lead to better adjustment and psychosocial outcome following acquired brain injury (Max *et al.* 1998; Wade *et al.*, 1995; Moore *et al.*, 1989).

### **5.5. Diversity in Emotion-Focused Coping**

Emotion-focused coping attempts to reduce emotional distress through dampening, venting, or directly challenging negative feeling states (Levy-Shiff *et al.* 1998). Strategies such as avoidance, minimization, distancing, selective attention, positive comparisons and eliciting positive value from negative events are all recognised strategies that cognitively dilute the threats posed by a stressful life event. Health related problems have been shown to be related with increased emotion-focused coping (Lazarus, 1966).

According to Lazarus & Folkman (1984), emotion-focused coping helps people maintain a sense of hope and optimism, sometimes to the point of unconscious self-deception, whereby people refuse to acknowledge the worst or its implications.

Lezak (1986) stated that ‘family denial’ following paediatric brain injury is not a pathologic response but rather a normal consequence of expectations of recovery derived from cultural exposure to illness. These expectations, based on past medical experiences and media portrayals of miraculous recoveries where the child is ‘restored’, alter expectations about recovery and affect levels of optimism. In contrast, acceptance constitutes a functional coping response particularly where the stressor (e.g. brain injury) must be accommodated and cannot be readily changed (Carver *et al.* 1989). Reported accounts of clinical experiences have indicated that conflicting and contradictory medical advice from experts often prolongs the healing process and delays the family’s level of acceptance (Ylvisaker, 1998). Interestingly, in a study by Baxter (1986), parents indicated that information received about their child’s illness from professionals was more important than emotional support.

## **5.6. Cognitive Reappraisal**

In situations like paediatric brain injury, where unrelenting strains may be resistant to coping strategies, the impact of the stress may be buffered by responses that function to control the meaning of the problem (Pearlin & Schooler, 1978). Cognitive ‘reappraisal’ is a common type of emotion-focused coping aimed at reducing stress, and involves the making of positive comparisons. The use of maxims such as “I considered how much worse things could be” and “count your blessings” act to diminish stress by changing the meaning of the situation (Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). When a stressor has been perceptually neutralised in this way, adversity is appraised either as being an improvement over the past or as a precursor for a brighter future (Carver *et al.*



1989). Furthermore, positive reappraisal can intrinsically encourage further engagement with problem-focused strategies.

### **5.7. Selective Ignoring**

Selective ignoring represents another perceptual strategy that people use to emotionally cope, but is rarely discussed in the coping literature. Selective ignoring is achieved by purposefully looking out for some positive attribute within a troublesome situation. An individual is able to cope by focusing attention away from the noxious and on to what is appraised as the worthwhile and rewarding aspects of the experience. Trivialising and thereby undermining the value of that which is harmful helps to amplify the importance of that part of the experience which is gratifying (Pearlin & Schooler, 1978).

### **5.8. Coping Taxonomy**

Although most stressful events elicit both types of coping, problem-focused strategies appear to triumph when a person feels that something constructive can be done, whereas emotion-focused coping tends to dominate when people view the stressor as something that must be endured (Folkman & Lazarus, 1980). The distinction between problem-focused and emotion-focused coping has been criticised for its simplicity as coping strategies have been found to fit more than two factors. Pearlin & Schooler (1978) devised a third division known as perception-focused strategies, which has been found in some research to be the most commonly reported approach by parents (Benn & McColl, 2004).

### **5.9. Social and Psychological Resources**

Coping resources constitute a cornerstone in the stress and coping research paradigm (Levy-Shiff *et al.* 1998) and also act as a moderating factor influencing the effects of stress and long-term parental adjustment. Despite this, empirical studies very rarely preoccupy themselves with adequately defining and distinguishing between social and psychological resources. Generally, resources refers to what is available to people in assisting them develop their coping repertoires (Pearlin & Schooler, 1978).

Social resources are resources found within a network of attachments that serve to improve coping in dealing with long-term challenges and stressors (Caplan & Killilea, 1976). Practical help, emotional support, information regarding methods of dealing with problems, and having those feeling normalised, can be accomplished by liaising with friends, family and neighbours. Children with chronic illness have been shown to report less behavioural problems when receiving high levels of emotional support than those receiving low support (Wallander & Varni, 1989). Psychological resources are the personality characteristics that reside within the self, and that people and families draw upon to survive sources of stress. Optimism, extroversion, high self-esteem, mastery, humour and the ability to focus on positive aspects of the child have all been identified in the empirical literature as helpful psychological resources aiding parental adjustment to paediatric illness (Scheier & Carver, 1985; Sloper & Turner, 1993; Brown & Hepple, 1989; Turnbull *et al.* 1985)

## **6.0. Summary**

There is no clear consensus in the stress and coping literature as to which coping strategies are most effective in resolving problems, preventing future difficulties, and abating emotional distress. Some studies have reported that problem-focused coping helps to diminish emotional distress whereas emotion-focused coping exacerbates it and hinders adaptation to chronic illness (Felton & Revenson, 1984). In contrast, other studies have documented emotion-focused coping as decreasing distress or that problem-focused coping reduces future problems but has little impact on emotional distress (Aldwin & Revenson, 1987). This ambiguity can be explained, in part, by design weaknesses inherent within traditional retrospective coping assessments such as the Ways of Coping Scale by Lazarus & Folkman (1980). Weaknesses involving the applicability of coping items for different contents of problems, and difficulties related to retrospective reporting such as selective memory, have been documented (Stone *et al.*, 1992; Carver *et al.* 1989).

In essence, Lazarus and Folkman's (1984) transactional model identifies primary and secondary cognitive appraisals, coping strategies, and the availability of support resources as central mediators in controlling stress - powerful enough to affect both short and long-term adaptation to chronic illness. The entire set of processes is intimately related and may cycle repeatedly in a stressful transaction (Carver *et al.* 1989) although problem-and emotion-focused coping can both facilitate and impede each other (Lazarus & Folkman, 1984). It has been posited that the essence of coping and adaptation is a process of change (Lazarus, 1993). This is clearly illustrated in the long duration of grief and the multiple ways of coping that take place over time preceding resolution of grief

and the eventual adaptation to the loss of a loved one (Schoenberg *et al.* 1975).

## **7.0 Parental Coping with Paediatric Chronic Illness**

### **7.1. Studying Families**

Parenting is generally viewed as ‘dynamic’, involving a series of actions and interactions performed by parents that include emotions, cognitions, and behaviours in cultivating children’s development (Dix, 1991; cited in Hoghughi *et al.*, 2004). This view of the family as dynamic or non-static, invites the application of a multitude of theoretical models of parent, child, and family adaptation following chronic illness. The literature is littered with an array of different and overlapping conceptual frameworks, including: family systems perspectives, the social ecological perspective (Kazak, 1989) and the disability-stress-coping model (Wallander *et al.* 1989). Central to these conceptualisations is an underlying emphasis on viewing the family as an interconnected whole, upon which stress impacts and can affect every family member. An inherent weakness in such models is the implicit subscription to a normative view of the family. Studies on parental coping have yet to fully acknowledge that modern families are diverse in structure, encompassing single-parents, extended families, co-cohabitating but unmarried couples, same-sex parents, foster parents and reconstituted families.

### **7.2 Parental Differences in Coping between Mothers and Fathers**

In keeping with the discovery of a bi-directional relationship between chronically ill children and their parents in the recovery process (Taylor & Stancin, 2003) research has

concentrated on exploring the availability and utilization of coping skills and resources of parents (Tansella, 1995). A limited number of mainly retrospective studies using summary measures of coping have sought to determine similarities and differences in the coping styles of mothers and fathers dealing with chronic illnesses such as leukaemia and muscular dystrophy in their children (Krauss, 1993; Thompson *et al.*, 1992; Kupst & Schulman, 1988). Many studies are based on a cross-sectional assessment at a single point in time although some studies have examined parental coping using a longitudinal design with multiple assessments (Levy-Shiff *et al.* 1989).

Hoghughli & Long (2004) reported a general theme among the research, alluding to fathers of chronically ill children using more reasoning strategies than mothers, such as seeking out information about the illness and educating their child about their illness. In comparison, mothers were identified as more likely than fathers to engage in physical and emotional activities that enabled their emotions to be released. Communicating with others and belonging to support groups were helpful strategies that mothers utilized more than fathers. Such gender differences appear congruent with other studies that have, more generally, alluded to the popular notion that men use more problem-focused coping than women while women use more emotion-focused strategies and social support (Vingerhoets & Van Heck, 1990; Hamilton & Fagot, 1988; Stone & Neale, 1984). The finding that women use more emotion-focused coping strategies than men should be treated with a certain amount of reservation.

Stanton *et al.* (1994) found that a great many emotion-focused items on commonly used coping scales are confounded with psychopathological content. Items such as 'becomes very tense' is devoid of any overt coping content and rather reflects emotional distress. Items such as these may be responsible for the understanding that women use more emotion-focused strategies, as women are socialised to acknowledge, and thereby report, their psychological distress more than men (Stanton *et al.* 1994).

In an effort to extend and replicate previous findings on gender differences in appraisal and coping, Porter & Stone (1995) asked whether gender differences in coping actually exist. As part of a larger longitudinal study, a sample comprising 79 middle-aged couples completed questionnaire booklets on a daily basis for 20 days. The questions in the booklet included a mood assessment, a daily event checklist, and the Daily Coping Inventory (DCI) devised by Stone & Neale (1984).

Porter & Stone (1995) found that men and women reported differences in the content of daily stressful events they came across, with women identifying more problems focused on the self, and men reporting more work-related problems. There were no gender differences in appraisal, with both men and women cognitively appraising their problems equally. No gender differences were found in coping across problem content categories, suggesting that it is the content of the problem, not gender, that determines the coping strategy selected. The findings contradicted previous research (Vingerhoets & Van Heck, 1990; Hamilton & Fagot, 1988; Stone & Neale, 1984) propagating the idea that women are more socialised to use emotion-focused coping strategies than men.

The empirical literature on gender differences in parental coping consists of broad-based questionnaire studies which ascertain information about general coping tendencies or strategies used across situations, and which fail to assess adequately and control the contents of problems experienced by mothers and fathers. The majority of studies have not controlled for cognitive appraisal, hence results alluding to differences between men and women in coping may be confounded by differences in appraisal. Results should therefore be interpreted cautiously.

According to a review by Nieuwenhuizen & Ridder (1994) the literature on gender differences in coping is inconclusive. There is an overall and significant dearth of literature drawing upon qualitative techniques examining gender differences among mothers and fathers coping with the same problem content on a daily basis. This is an important gap as research indicates that minor events or daily stressors are more strongly correlated to psychological symptoms than major life events (Brantley & Jones, 1993; Kanner *et al.* 1981). This is particularly true in the case of paediatric encephalitic brain injury, which can cause multiple and ongoing stressors for parents over many years (Wallander, 1995; Moore *et al.* 1989). Perhaps because of the complexities of applying qualitative techniques in this area, empirical studies continue to centre on multivariate research designs generating results imbued with breadth rather than depth.

### **7.3 Parenting Physically Disabled Children**

Gordon *et al.* (1992) examined stress, appraisal and coping in mothers of disabled and non-disabled children. Sixty-nine mothers of physically disabled children were compared with 63 mothers of non-disabled children. Commonly used questionnaires measuring coping, appraisal and negative symptomatology were administered. One of the three hypotheses tested stated the problem-focused coping strategies would be associated with decreased psychological distress in mothers of disabled children when dealing with stressful parenting situations. Results indicated that this negative relationship was supported, even after controlling for differences in types of stressors. Planning and problem-solving skill appeared to fit more effectively with the appraisals of mothers than emotion-focused strategies. In contrast, a positive relationship was found between emotion-focused coping and psychological distress for certain strategies – supporting similar findings by Felton & Revenson (1984). Gordon *et al.* surmised that mothers may indulge in certain emotion-focused strategies that lock them into a cycle of self-blame that prevents them from using their energies to cope in a problem-focused way.

The strength of Gordon *et al.*'s (1992) study resides in the strong implications the results have for clinical interventions, which many studies fail to make. They proposed a cognitive-behavioural programme designed to help parents cope, including components focused on providing information appropriate to their child's age and place in the illness trajectory. Alongside this, appraisal and coping training, with an emphasis on positive reappraisal and problem-solving, was proposed as critical, particularly with an emphasis on helping mothers make appropriate matches between appraisals and coping strategies.



Bregman (1980) proposed many strategies reported by parents as helpful in coping with progressive childhood illness, the majority being problem-focused. Strategies included taking each day as it comes, keeping well-informed, maintaining daily life as normal as possible and seeking out the best options for their child's health and welfare. Miller *et al.* (1992) provided findings congruent with those of Bregman (1980), confirming that problem-focused strategies such as confrontation, planning and seeking out social support are predictors of maternal and paternal adjustment, whereas emotion-focused strategies are associated with higher rates of parental distress. However, a number of studies looking at parents of children with developmental disabilities have demonstrated that certain cognitive strategies such as restructuring and positive self-praise are adaptive to lowering psychological distress (Affleck & Tennen, 1993; Brown & Hepple, 1989; Bregman, 1980).

#### **7.4 Parental Coping with Paediatric Brain Injury**

Benn & McColl (2004) investigated parental coping following the onset of acquired brain injury in their child using a cross-sectional design based on a sample of 30 parents of 15 children. Parents were interviewed separately using the Ways of Coping Scale (WOCS) by Lazarus & Folkman (1980). Results indicated that parents most commonly used perception-focused coping strategies, aimed at altering the perception of the situation. Mothers were found to have a more extensive coping repertoire than fathers, thus potentially coping more effectively with their child's brain injury. A statistically significant positive relationship was found between instrumental support and emotion-focused coping i.e. parents who received practical support were more likely to engage in

emotion-focused coping. This corroborated previous research on the importance of instrumental support in the day-to-day adaptation of parents with a chronically ill child (Heninen & Kyngas, 1998).

The prevalence of negative correlations between maternal and paternal coping was found by Benn and McColl (2004) to suggest a complementary coping relationship, whereby when one parent utilised a particular coping strategy, the other parent tended not to use the same tactic. They cited the example of one parent engaging in active problem-focused coping, while the other parent seized the opportunity to gain respite from the situation. A positive relationship was also found between perception-focused strategies and family cohesion, suggesting that families who successfully adapt and cope are those who are intact and more cohesive. Family characteristics such as cohesion and adaptability to change are incredibly important in helping families dealing with brain injury to resist or adapt to crises (Minnes *et al.* 2000; Holohan & Patterson, 1991). If the family fails to accommodate the need to change, this may become an additional source of life strain (McCubbin & Patterson, 1983).

Benn and McColl's (2004) research provides a valuable empirical contribution to the neglected area of parental coping with paediatric acquired brain injury. However, the results are limited. They are merely descriptive and derived from a biased sample of 15 financially secure and cohesive parental pairs, hence making generalisation to poorer or less cohesive parent couples difficult. Curiously, the researchers did not report the aetiology of the acquired brain injury under scrutiny or its severity. Due to the small

sample, the study could have been extended by encompassing semi-structured interviews with the parents - providing qualitative extrapolations which may have increased the explanatory value of the findings.

### **7.5. Qualitative Research Studies on Parental Coping**

In a study examining a sub-group of parents of children with central nervous system (CNS) tumours, Vance *et al.* (2004) used interpretative phenomenological analysis (IPA) as a qualitative approach to examine, in part, how parents cope with the tumour from their own perspective. Eight mothers, one father and two mother-father pairs were included in the study. Results indicated that all parents coped in a problem-focused way; helping their children adjust to their difficulties in a practical way aimed at solving their problems. The absence of emotion-focused strategies (e.g. denial, avoidance, suppression) was explained by the parents having lived with their child's illness for some time, rather than being newly confronted by it. The stage in the illness or where the child is in the illness trajectory has a pervasive influence on how parents and families respond and cope (Gravelle, 1997). Data extracted from the interviews illustrated that Vance *et al.*'s (2004) research offered an in-depth understanding of parental 'lived' experience, but was weakened by a small sample that precluded the results from being generalizable.

In an extensive Irish study, Heary *et al.* (2003) examined the psychosocial experiences of children and families living with acquired brain injury during childhood and adolescence. The majority of the children acquired their injuries due to road traffic accidents, although

eight children had brain injury due to non-specified infection. Based on a large sample, including 30 parents of children who attended a rehabilitation hospital, semi-structured interviews were conducted. Interview data were transcribed and content analysis was used to analyse emerging themes. Part of the study aimed to ascertain parental perspectives on coping with paediatric brain injury.

Findings from the interviews illuminated parental coping strategies based on a general need to 'get on with things' or to 'take it day by day'. The authors of the research reflected upon a sense that parents coped because they had to; it was a necessity rather than a choice. Characteristics such as perseverance, determination and willpower were identified as helpful states in maintaining coping behaviour. Social support appeared to be more readily used by parents than emotional support, which was rarely cited. This latter finding supports the statistically significant positive relationship between instrumental support and emotion-focused coping found by Benn and McColl (2004). Social support from friends, neighbours and family in the form of tangible services such as gifts, food, transport, babysitting and money was highly valued in promoting coping. Further themes revealed that some parents coped through receiving support from significant others at the start of their child's illness trajectory, while many preferred to cope by managing alone and being self-reliant.

Heary *et al.* (2003) commented that a small number of parents coped by talking about their feelings to others, and that many parents felt able to share the responsibility of caring for their child with their partner. In being able to maintain coping behaviour, a

sense of hope and optimism was regarded as essential in providing a life-line to face future struggles. Opportunities to take time-out from caring duties, through recreational activities, were considered vital for parents' emotional well-being. The research indicated that inadequate consideration is still afforded to understanding how parents cope with paediatric brain injury within its social context; this has important implications in terms of the lack of clinical interventions available to these parents. Heary *et al.* (2003) highlighted this by citing parents' concerns:

“Parental reports imply that insufficient attention is given to the manner in which children and families cope with and adjust to the challenges they face following acquired brain injury” (Heary, *et al.* 2003: 102)

The value of Heary *et al.*'s (2003) research resides in the fact that it adopts a broad remit and represents a rare case whereby a qualitative methodology has been used empirically to offer an innovative and in-depth illustration of the challenges faced by families of children with acquired brain injury. In part, it richly highlights coping as a primary theme of social and psychological importance and, in doing so, shines a light on the hidden nature of acquired brain injury in children. Methodologically, it was not clear whether the parents interviewed were mothers and fathers. More significantly, the researchers highlighted the need to validate empirically the themes generated in their research.

## 8.0. Summary

Coping is a dynamic and shifting process. It comprises a set of cognitive and behavioural strategies that people use alongside social and psychological resources to help manage stressors or situations appraised as taxing (Porter & Stone, 1995). Chronic illnesses in children including diabetes, asthmas and cystic fibrosis often result in 'paediatric parenting stress' and wider family disruption (Streisand *et al.* 2001). Viral encephalitis is the cause of acquired brain injury for a number of young children each year, exacting ongoing stressors for parents. Like other chronic health conditions, encephalitis represents a multidimensional experience that requires the successful organisational and emotional adjustment of the child and family (Tansella, 1995).

Parenting in modern society is a skill undertaken by a wide range of families which are increasingly diverse in organisational structure. Attention in the empirical literature has shifted away in recent times from simply documenting the psychological and social burden of acquired brain injury to examining moderators and predictors of outcome (Moore, *et al.* 1989). Understanding how parents make use of the social support available to them, and how they cope with the stressors engendered at the different stages of the child's illness trajectory, are just two central determinants of outcomes.

Taken together, studies on coping in parents of children with chronic illness indicate inconclusive findings about which coping strategies are the most used and successful in ameliorating paediatric stress. Experimental studies have tended to focus on maternal coping to the neglect of fathers. Furthermore, reports of differences in using certain

coping strategies between men and women are often contradictory, having been derived from broad-based questionnaire studies which are methodologically weak and inconsiderate of the appraisal process. There is a continuing scarcity of research addressing positive family outcomes following paediatric brain injury, coupled with a significant gap of empirical studies using qualitative techniques to understand parental coping.

## **9.0 Conclusion and Future Research**

On perusal of the literature, the following points can be made: (i) infectious diseases tend to be covered only briefly in the literature and with a predominant focus on HIV and AIDS. Acute encephalitis is mostly mentioned in the context of its neurological sequelae or when outlining behavioural adjustment following herpes simplex viral encephalitis; (ii) when compared to the large body of research on adult acquired brain injury, there is a significant and overall gap in empirical studies examining the coping strategies of mothers and fathers managing paediatric acquired brain injury; and (iii) no studies have examined the coping process of mothers and fathers of children with post-encephalitic brain injury; their recovery path remains relatively unexplored compared with children injured through more traumatic experiences like road traffic accidents.

Future research would best be directed at using more flexible approaches to data gathering, including semi-structured interviews of mothers and fathers or focus groups comprising wider family members. The use of qualitative techniques would offer an

appropriate and useful way of discovering the hidden experiences of those affected by encephalitic brain injury, and how these experiences are tolerated, minimised and/or ultimately mastered by parents struggling to adjust. Specifically, interviews with parents combined with observational techniques would be useful in examining the interactions between parents and their injured children, illuminating and identifying points of crisis within the coping process. Finally, longitudinal studies comprising regular assessments would provide a valuable insight into the coping process across time.



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## **Section2**

### **Research Report (OPTION 1)**

**Parental Coping with Paediatric Encephalitic Brain Injury**

# **Parental coping with Paediatric Encephalitic Brain Injury**

**Stephen Bainbridge**

## **ABSTRACT**

This study aimed to explore how parents cope with their children's encephalitic acquired brain injury, and whether any differences in coping exist between mothers and fathers.

Semi-structured interviews were conducted with five parents who volunteered via the Encephalitis Society to take part in the study: two spousal couples and a single mother. Interviews were transcribed verbatim and analysed according to the grounded theory method (Charmaz, 2003). Main categories were generated from the analysis and a core category was identified entitled 'Thinking Positively'. A process model of coping was developed. All parents interviewed appeared adjusted and were coping at that time. Data analysis revealed gender differences: the mothers were shown to take on more coping demands and engage in more problem-solving activities related to their child's brain injury than did the fathers.

Implications for NHS and clinical psychology services in understanding how parents cope are outlined. Points raised include: (i) parents wanted professionals to listen to their opinions and needs more carefully and provide them with accurate information on encephalitis during the early part of their child's illness; (ii) they required more social support in the form of practical help with coping once the child had returned home from hospital; and (iii) their comments alluded to the need for improved 'signposting' of services to help them take a break from having to constantly 'fight' for knowledge and solutions on behalf of their child.

In discussing the ways in which parents cope with the stress caused by their children's brain injury, a number of theoretical concepts have been drawn upon, largely from coping theory (Lazarus and Folkman, 1984). Suggestions for future research in parental coping with paediatric brain injury are made, with particular reference to interviewing parents together and, wherever possible, the brain-injured child as well.

**KEYWORDS:** *Encephalitic brain injury, coping, parents, grounded theory, support*

## **1.0. INTRODUCTION TO THE CURRENT STUDY**

### **1.1. Encephalitic Acquired Brain Injury**

Clinical reports indicate that the majority of people afflicted by an encephalitic illness make a full recovery, especially those diagnosed with bacterial encephalitis which is less destructive than viral encephalitis and can be easily treated with antibiotics (Booss & Esiri, 1986). Viral encephalitis is rare but can cause non-focal, diffuse or multi-focal brain damage, resulting in long-term problems with thinking, memory, behaviour and emotional functioning (Taylor & Stancin, 2003). Children aged one year or less and adults aged 55 years and over are the most vulnerable to life threatening complications from encephalitis. More significantly, encephalitis in young children is likely to result in some damage to nerve cells, resulting in varying degrees of acquired brain damage, which may necessitate long term supportive care and therapy.

Approximately 350 cases of all encephalitis admissions to hospital in the U.K each year are children; the majority are under the age of five (Davison *et al.* 2003). The medical literature indicates that despite antiviral treatment with drugs such as Acyclovir (Zovirax), viral encephalitis results in brain damage, to varying degrees, for a significant proportion of these children. A lack of routine surveillance systems within the NHS means that no case definition is available for encephalitis and no official statistics exist of the number of children who recover without psychological or neurological problems.



To date, inadequate consideration in the empirical literature has been given to understanding the impact of viral encephalitis as a cause of acquired brain injury in children. One reason for the dearth of encephalitic research among health care professionals may be the fact that patients are usually treated in departments of medicine or infectious diseases, instead of neurological units where neuroscientists and psychologists are more likely to be found (Hokkanen & Launes, 2000). This has led to a general ignorance about the impact of encephalitis on the psychological well-being of families and how they cope.

Acquired brain injury has been defined as:

“... injury to the brain which results in deterioration of cognitive, physical, emotional or independent functions. It can occur as a result of trauma, hypoxia, infection, substance abuse, degenerative neurological disease or stroke” (Commonwealth Department of Human Services and Health, 1994: 26, cited by Heary *et al.* 2003: 2).

According to the Children's Brain Injury Trust (CBIT), 20,000 children in the U.K each year suffer an acquired brain injury, either as a result of accident (e.g. traumatic brain injuries) or illness (e.g. strokes, tumours and infections).

## **1.2. Systemic Impact of Paediatric Acquired Brain Injury on Families**

Chronic illness in children, irrespective of aetiology, naturally disrupts family functioning. Kazak (1986) highlighted the systemic nature of childhood illness, positioning the child at the centre:

“The chronically ill child is a focal point only in an inter-related, dynamic system of parents, siblings, extended family, friends and health care professionals” (Kazak, 1986:265).

A significant body of literature exists pertaining to the impact of paediatric acquired brain injury on parents’ social, psychological and family morbidity (Gottman, 1993; Kazak & Marvin, 1984; Quittner *et al.* 1992; Harris *et al.*, 1989). This research is bedevilled by inconclusive findings, some alluding to significant sequelae in parents while some studies have not resulted in such findings. Empirical research has concentrated on exploring the availability and utilization of the coping skills of parents who often face a multitude of unrelenting stressors that may be resistant to coping strategies (Tansella, 1995).

## **1.3. Coping Literature**

Theoretical and conceptual definitions of coping in the literature have been influenced over the years by continuing arguments concerning the exact properties that it

comprises. The prevailing and most dominant of these currently is the conceptual understanding offered by Lazarus & Folkman (1984) who define coping as constantly shifting cognitive behavioural strategies used to manage stressors that are appraised as exceeding personal resources. These strategies are seen as being either emotion-focused or problem-focused (see summary section 1.9.0 of Review Article).

Review papers refer to the finding that positive coping behaviours are associated with better adjustment and psychosocial outcome following acquired brain injury (Max *et al.* 1998; Wade *et al.* 1996; Moore *et al.* 1989). In the diverse history of research on parents of children with chronic illness, most studies include standardised measures of coping, involving quantitative analyses comparing parents with chronically ill children with healthy controls. Furthermore, samples in these studies have included children with different acquired and chronic illnesses, and varying in age at diagnosis, thereby making it difficult to generalise the results. Not surprisingly, these global between-group comparisons do nothing but accentuate the negative consequences of chronic illnesses in childhood. None of these studies has specifically looked at parental coping with encephalitis in children.

#### **1.4. Qualitative Studies on Parental Coping with Paediatric Brain Injury**

Karpman *et al.* (1986) conducted one of only a handful of studies in the literature focused specifically on parents of adults with acquired brain injury. Based on in-depth interviews with mothers of ten adults with traumatic brain injuries caused by car

accidents, a range of themes pertaining to coping was found. These included maintaining hope and a positive attitude, acknowledging internal strengths, increasing family cohesion and accessing social support.

Only one recent empirical study (e.g. Heary *et al.* 2003) has used a qualitative methodology to examine the coping experiences and strategies per se of parents managing paediatric acquired brain injury, although this constituted a small fraction of a much larger analysis exploring themes of 'impact'. Heary *et al.*'s (2003) research reported that parents felt coping was a necessity rather than a choice, describing a variety of strategies they used to manage their child's brain injury, including maintaining optimism and hope. Importantly, the research reflected parents' feelings that insufficient attention by health care professionals is afforded to how families cope following acquired brain injury, both in terms of a lack of understanding, information and support. It was unclear from the research whether the parents interviewed were mothers, fathers or a mixture of both.

### **1.5. The Need to include Fathers**

It is widely recognised within family systems literature that families with chronically ill children are normal families forced to cope with extraordinary circumstances (Eiser, 1994). There exists a well-established premise that acquired brain injury impacts on all members of the family organisation (Lezak, 1988). As such, it has been argued that studying both parents is required to properly understand parental coping behaviour (Taanila *et al.* 1996; Quittner, *et al.* 1998), although a comprehensive

review of the literature on gender differences in coping indicates it is inconclusive (Nieuwenhuizen & Ridder, 1994)..

Historically, literature that reports on the wider familial impact of adult acquired brain injury (Perlesz *et al.* 1999; Brooks, 1984; Lezak, 1988) has focused exclusively on the experiences of the primary caregiver, namely the mother or female partner. Paternal caregiving and coping is typically ignored or given low priority within this literature. This requires attention in order to promote improved understanding of the relationship between male and female coping, as well highlighting the importance of developing supportive services to assist men in managing the stress created by caring for a child with a brain injury.

## **1.6. The Clinical and Policy Context**

In 2002, the British Society of Rehabilitation Medicine (BSRM) proposed guidelines for rehabilitation and continued support for patients with acquired brain injury and their families. These pertained to adults of working age only. Despite an exemplar on paediatric acquired brain injury arising from the National Service Framework (NSF) for Children, Young People and Maternity Services (2004), there is still no national plan or policy for treating and managing children and adolescents with acquired brain injuries in the National Health Service (NHS). Equally important, the Department of Education and Science fails to recognise paediatric acquired brain injury as a specific disability category in its own right; hence the service requirements of these children are not clearly delineated in two major services.

It has been documented in the literature that parenting children with a chronic illness represents a crucial area of interest for clinicians and researchers; children and adolescents with chronic medical problems constitute a considerable proportion of health care patients (Streisand & Tercyak, 2004).

#### **1.6.1. Implications for NHS Clinical Psychology Services and CAMHS**

Despite the prevalence rates of children with acquired brain injury in the U.K, clinical psychology services are not currently in a position to provide for this group in a systematic way. Although children with acquired brain injury as a result of viral encephalitis can be referred to local child and adolescent mental health teams (CAMHS) for help with psychological problems arising from their illness, comparatively few are seen (Stallard *et al.* 2001). Children with acquired brain injuries are often poorly served beyond the acute phase of treatment (Greenwood *et al.* 1994).

### **1.7. Understanding Parenting Stress**

Streisand *et al.* (2001) commented that understanding how parents cope with paediatric stress is vital. Parents are children's most essential health resource, helping them manage the illness while continually bringing their medical needs to the awareness of health care professionals. In essence, mothers and fathers play a vital role in the identification and management of behavioural concerns, the quality of their communications with professionals on such problems often determining if and when

resource services are offered (Hoghughi & Long, 2004). In modern paediatric practice, parents are routinely instructed to give their sick child prescribed treatments and to implement preventative measures; they are, in effect, recruited as part of the medical team (Gustafsson, 2005).

Future research would be best directed at developing a greater awareness of coping strategies used by parents. This could hopefully provide a focus for devising models of assessment and clinical/rehabilitation interventions, aimed at identifying those parents at risk of psycho-emotional sequelae and who would benefit from specific support in managing their post-encephalitic child. More specifically, Streisand & Tercyak (2004) commented that health care providers should work towards the remit of helping parents maintain a sense of normality.

The empirical literature detailing the impact of acquired brain injury on parents' psychological morbidity is permeated by inconclusive findings (Sloper & Turner, 1991; Kazak & Marvin, 1989; Spaulding & Morgan, 1986). Future research aimed at understanding how mothers and fathers cope with health related stressful life events, would provide useful information in explaining the variability in mental health illness rates.

## **1.8. The Current Study**

Few empirical investigations into the impact of paediatric acquired brain injury have been conducted to date (Wade *et al.* 1995). Only a handful have adopted a qualitative

methodology (Karpman *et al.* 1985; Vance *et al.* 2004; Heary *et al.* 2003) and largely to explore the notion of ‘impact’. Much less is known about the coping strategies *per se* of parents in managing paediatric brain injury. Furthermore, previous research has largely focused on maternal coping, to the neglect of fathers. This imbalance requires remedy to reflect the diversity in modern family structures pertaining to caregiving.

Research based on semi-structured interviews using qualitative techniques allows for small numbers of participants to be recruited. The researcher is not restricted in asking inflexible questions; therefore a much deeper understanding of the phenomena under investigation can be engendered than would be possible through conducting research based upon broad-based questionnaires of coping.

The lack of qualitative studies in the literature impedes our understanding of the experiences of parents following viral encephalitis in a child as there is inadequate knowledge about how best to understand and support their ‘lived everyday experiences’. Appreciating and accepting the current challenges that mothers and fathers have to confront and ultimately cope with is a necessary step in developing long-term services.

Based on the premise that stress is multidimensional (Lazarus & Folkman, 1984), exploring and understanding how parents appraise their child’s encephalitis is the cornerstone in appreciating the stress they face. Importantly, what is missing in the current research literature is an examination of how parents cope with their child’s encephalitic brain injury from their own unique perspective. This can most usefully be met by a qualitative research approach that can sensitively consider the social and



systemic context that inherently shapes and informs coping behaviour after diagnosis and long after discharge from acute care services.

## **1.9 Research Aims**

The present research aims to better understand the coping process in parents. Based on a qualitative methodology using in-depth interview data with mothers and fathers, the following research questions are targeted within the study:

**Primary question:** How do parents cope with their child's encephalitic brain injury?

**Secondary question:** Are there gender differences in the way mothers and fathers cope with their child's encephalitic brain injury?

## **2.0 METHOD**

### **2.1 Recruitment**

Access to a database of children with a diagnosis of encephalitis was obtained from the Encephalitis Society – Action for Support, Awareness and Research (registered charity No: 1087843), with permission from its National Co-ordinator. Parents were selected if they met the following criteria: (i) the child had a diagnosis of viral encephalitis (aetiology known or unknown) and lived at home; (ii) the child was aged three years or older at the onset of illness; (iii) two parents lived with the child (not necessarily the biological parents) and had done so since the onset of the illness; (iv) the child showed normal development prior to onset of illness; (v) parents were white Europeans and fluent in English; and (vi) parents of the child lived in the East Midlands and were willing to be interviewed.

These criteria were selected because children under the age of five are the most vulnerable age group to contracting encephalitis; children over the age of three are at risk of losing previously learnt skills leaving them neurologically injured. Parents of different ethnic backgrounds were excluded due to evidence of cultural differences in coping behaviour relating to eastern cultures. The aim of the current research was not to examine cultural dimensions but rather focus on the normative values pertaining to coping that are inherent within white western cultures only. This allows direct comparisons to be made with previous research on coping with chronic illness.

Twenty parent couples were approached initially by the Encephalitis Society via letter on behalf of the principal researcher and the Society (see Appendix 1 & 2). A participant information sheet outlining the details of the study was included and sent separately to each mother and father (see Appendix 3). Two parent couples contacted the researcher and agreed to participate. A second search of the database identified a further three sets of parents in the geographical area, of whom one volunteered to participate. Parents were not asked why they did not wish to opt into the study.

Ethical approval was obtained from the NHS Trust Local Research Ethics Committee in September 2004 (see Appendix 4). Approval from the Encephalitis Society Advisory Panel and Research Committee was gained in early October 2004 (see Appendix 5).

## **2.2 Participants**

### **2.2.1. Parents**

Two parent couples and one single parent mother (total  $n = 5$  comprising three mothers and two fathers) were interviewed<sup>1</sup>. Five participants is the minimum for grounded theory research, as recommended by Turpin *et al.* (1997). Difficulties in recruiting participants centred around: (i) finding that the Society's database did not store details on whether parents were single, separated or part of a couple; (ii) being restricted in sampling from the East Midlands area due to practical constraints; (iii) finding children not meeting the inclusion criteria or having dominant sequelae associated with epilepsy only; and (iv) concern within the Encephalitis Society that

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<sup>1</sup> The researcher had planned to interview three couples; however, due to unforeseen circumstances the third couple separated.

following-up invitational letters might distress a family where a child had died from their illness.

Saturation of the data, which should guide and determine the number of participants interviewed, was not achieved in this study. Saturation is reached when data sets reveal no new categories or relationships between emerging themes (Glaser and Strauss, 1967). The implications of not reaching saturation are outlined in the discussion section of this report.

The parents were interviewed separately, allowing their unique experiences as a mother or father to be heard and listened to properly. The mean age of the parents was 37 years (range 33-40 years). The mean duration of their relationships was 12 years (7-17 years). One couple was first time married and the other family was reconstituted following the break-up of both the mother's first partnership and the step-father's previous relationship. The final participant was an unmarried mother, who had recently separated from her partner. All parents were working class and had appeared not to have continued their education after secondary school.

### **2.2.2. Child Demographics**

The median age of the children (M = 2; F = 1) was nine years (range 8 years 2 months to 10 years 5 months). The mean number of years since the onset of the children's illness was 5.3 with a range of 3-7 years. Parents reported that on admission to hospital their children had a cumulative Glasgow Coma Scale (GCS) between five and ten. A GCS score of three to eight has been defined as an indicator of severe brain injury (Wood & McMillian, 2001). The Glasgow Coma Scale is a 15-point scale used

to assess a patient's level of consciousness by evaluating three behavioural responses including eye opening, verbal response and motor response. Each is rated on a one to five scale of severity which is summed to provide a cumulative score.

Each child had a Statement of Special Educational Needs and attended special needs schools. Two children had an additional diagnosis of epilepsy as a consequence of their injury and one child had lost their speech completely. The children had behavioural problems to varying degrees of severity, including sexual disinhibition and challenging and physically aggressive behaviour. Physical disabilities related to loss of fine motor control of upper limbs only. None of the children required a wheelchair. One mother reported her child to have serious mental health problems, including depression and obsessive compulsive disorder. Parents described their children as having significant developmental delay and learning difficulties as a result of their brain injury. To help manage their children's behaviour, the parents had ongoing relationships with local authority and NHS services such as CAMHS (Child Adolescent Mental Health Service).

### **2.3. Data Collection**

A semi-structured interview schedule was developed before the interviews (see Appendix 6). Comprising a number of areas of interest, derived in part from the empirical literature on chronic illness and coping, questions were carefully worded in order to (i) limit biasing the parent's responses and (ii) allow for the area of interest to be comprehensively explored.

The interviews were conducted by the principal researcher. Individual semi-structured interviews were conducted in the evenings with each parent in their own homes - this allowed for uninterrupted time as the children were in bed. Before the interviews began, each parent read and signed a consent form agreeing to participate (see Appendix 7). Each partner of the parent couple was interviewed separately, the mother first. Interviews ranged in length from 50 to 110 minutes. During the conduct of the interviews, the researcher was intuitively sensitive to the emotional nature of the material being discussed and paced interviews accordingly. Despite this, one father and one mother became tearful while talking and asked for the tape to be stopped until they regained their composure.

The structure of the interviews followed an open-format, in line with qualitative research tradition. Basic demographic and neurological information about the children was gathered by means of an initial series of closed questions. Closed questions designed to elicit concrete information are appropriate in order to avoid recording material that is highly abstract or unfocused (Hollway & Jefferson, 2000). More open-ended questions were asked next aimed at encouraging flexibility in allowing parents to follow up their interests or concerns (Smith, 1995; Burman, 1994).

All interviews were audio-taped and transcribed verbatim by an experienced secretary using guidelines recommended by Burman (1994). The principal researcher checked through the transcripts while listening to the tapes and correcting typing mistakes. Identifying details were removed. The tapes were wiped in accordance with the research ethics protocol.

## **2.4 Grounded Theory as a Qualitative Method**

To explore effectively the coping experiences of parents, the principal researcher selected grounded theory as the method to analyse interview material. Grounded theory is a distinctive procedure used for analysing textual data, geared towards producing rich and complex conceptual and multi-faceted categories, upon which a model or theory of the phenomena under investigation is built (Charmaz, 2003). The main principles of the method include owning one's perspective through the process of reflexivity, close and systematic attention to detail in the raw data, and developing a conceptual understanding of the phenomena which is beyond merely description (Charmaz, 2003; Henwood & Pidgeon, 2003; Strauss & Corbin, 1998).

Data collection, analysis and theory-building occur simultaneously in grounded theory, through the methodological commitments of constant comparison and theoretical sampling (Pidgeon, 1996). At the end of analysis, the emergent 'grounded' theory should resonate with the actual lived experiences of those investigated but be conceptualised in a way that makes it accessible and understandable to other individuals. It should be generalizable to other settings and stimulate further questions for research.

## **2.5 Rationale for using Grounded Theory**

Grounded theory was selected as the method of choice for a number of reasons.

Firstly, the approach is sensitive to focusing on the importance of understanding the meaning of experience, actions and events as interpreted through people's own frames

of reference within their social contexts (Henwood & Pidgeon, 1995). This was vital in discovering how parents cope with their child's encephalic brain injury, particularly the experiences of fathers, which have been largely overlooked by researchers in the past. Secondly, theory-generation is integral to the grounded theory method; it naturally lends itself to research aimed at the practical applications of its findings. Given the lack of support services and resources for parents of children with brain injury (Greenwood *et al.* 1994), the researcher was keen to achieve recommendations for positive change. Thirdly, the method was selected because it represents a systematic approach to data collection, and this was useful as the researcher had little experience of qualitative research. Finally, grounded theory was preferred because it aims to unearth processes within the data, unlike alternative approaches such as IPA (Interpretative Phenomenological Analysis) which concerns itself with themes generated in the context of individual experience (Smith & Osborn, 2003).

## **2.6 Procedure: Data Analysis**

### **2.6.1 Line-by-Line Coding**

Transcripts were analysed according to the principles of the Grounded Theory approach to the analysis of textual data (Charmaz, 2003; Strauss & Corbin, 1998). The transcripts were analysed in the order the interviews were conducted. This process was undertaken initially by line-by-line coding. The principal researcher split the text into small 'meaning units' aimed at identifying the key feature or concept of each given line. These units were ascribed a code which was written on the right hand side of the transcript. Once initial coding of a transcript was complete, the researcher divided the transcript into paragraphs and recorded all the initial codes on to a



computer; using a computer provided a permanent record which could be flexibly manipulated for the purpose of analysis.

### **2.6.2 Focused Coding**

Focused codes were selected from line-by-line codes to represent an initial synthesising of the data (Charmaz, 2003). These were added to the computer using a text box. As coding continued and similar themes within the transcripts occurred repeatedly, the researcher coded larger units of meaning with more abstract and overtly analytical focused codes (for an example of coding see Appendix 9). Focused codes and their subsumed line-by-line codes were grouped together within and across transcripts. It was at this stage that the researcher started a move towards working more conceptually in developing general categories and sub-categories.

### **2.6.3 Category development**

The principal researcher began to develop categories after the first three interviews had been coded. Categories were generated by grouping summary focused codes within and across transcripts and then saved on the computer as a permanent record of category development. Developing categories involved the process of constant comparison. Constant comparison involves comparing transcripts and their data prospectively as well as retrospectively in order to ensure that conceptual development fits with the data (Pidgeon, 1996).

#### **2.6.4 Memo-Writing**

Memo-writing is the process at which categories are defined by their analytical properties. It is at this point that the researcher attempts to make overt the implicit processes subsumed by the codes or categories, all the time looking for relationships between the data, codes and categories. The use of raw data from the transcripts is used to extricate and support the analysis, thus ensuring the development of a 'grounded' theory. Through the process of memo-writing, gaps in the research may be highlighted, and possibly filled by theoretical sampling. Theoretical sampling is the selection of further participants on the basis of emerging theory (Charmaz, 2003).

#### **2.7. Theoretical Sampling**

From the outset, the principal researcher was aware that theoretical sampling would not be possible due to the limited number of parents who volunteered to participate in the research. However, due to unforeseen circumstances, the third and final parent couple who volunteered to participate separated. The father had not lived with his family for a number of months. Following two telephone conversations explaining the nature of the study, the researcher was optimistic that the third father would still agree to be interviewed. Unfortunately, in the last week of the research he declined to participate without saying why. Due to time constraints and a lack of more subjects, the researcher was unable to achieve the ideal of six participants. Nevertheless, this left his wife, who described herself to the researcher as a single parent family. The inclusion of a single parent as an alternative to the two parent couples was an example

of theoretical sampling fortuitously. The researcher welcomed this as potentially adding further diversity and depth to the eventual theoretical account.

## **2.8 The Position of the Researcher**

The researcher is a male trainee clinical psychologist in the final year of doctoral training. Having previously worked in a rehabilitation and long-stay unit for brain-injured adults, the researcher found that families were rarely asked how they perceived their relative's brain injury, how it made them feel and/or how they were coping, or not coping. Fathers, brothers and sons visiting the unit appeared on the surface to be the most visibly upset, more than their female counterparts, who would often spend their time hurriedly engaged in practical tasks caring for their relative. These experiences provided a snapshot of possible differences in both 'division of labour' and 'emotional containment' between men and women. This engendered curiosity as to which processes were guiding and directing such behaviour, although the researcher had blindly interpreted these to be about coping.

In terms of epistemological stance pertaining to the current research, the researcher was more closely aligned to the critical realistic position than social constructionist. The researcher believed that accounts obtained by parents represented their own reality and lived experiences, although he accepted that within the production of these accounts an inherent subjectivity existed.

## 2.9 Reflexivity

To underscore the importance of reflexivity in qualitative research, after each interview the principal researcher made notes in a Research Journal, chronicling thoughts and feelings engendered by the interviewing encounter. The Journal was also a useful resource in allowing on-going and explicit interpretations of the data to be made. This is important in ensuring a level of transparency is brought to the research process (Elliott *et al.* 1999). An extract from the Research Journal showing reflection on emerging ideas following an interview can be seen in Box 1.

### **Box 1. Extract from Principal Researcher's Journal**

*7<sup>th</sup> April 2005 – Interview with Mary  
Just completed the fifth and final interview with the mum  
and feeling slightly emotional. I was impressed by how  
eloquently she spoke and she seemed really resilient despite  
all her experiences. When she mentioned about watching  
documentaries, she said this provided her with knowledge  
to access more services for her girl. This has reminded me  
and made explicit something similar said by the first mother  
(Emily). I need to go back and check the function of  
'information gathering' and whether it's about extending  
one's coping repertoire in some way.*

## 3.0 Summary: The Methodological Aim

Grounded theory was used to develop a model which (i) represented parents' experiences (ii) was grounded in examples from individual interviews and (iii) was experienced by most participants in the study.

## **4.0. ANALYSIS**

### **4.1. Overview**

This study aimed to explore how parents cope with their child's encephalitic brain injury, and whether any differences in coping exist between mothers and fathers. From the grounded theory analysis, a process model conceptualising parental coping is presented. One core category emerged from the data with four main categories comprising intermediate and lower level sub-categories. Quotations embedded within the analysis provide illustration to the categories described. For ease of reading, page and line numbers of each transcript are given.

The core and main categories developed by the analysis were identified in the interview transcripts of the five parents. The intermediate and lower-level categories were identified in the texts of at least three parents. There was one exception, concerning the '*Segregation*' category which detailed the experiences of the single mother in the study.

### **4.2. The Process Model**

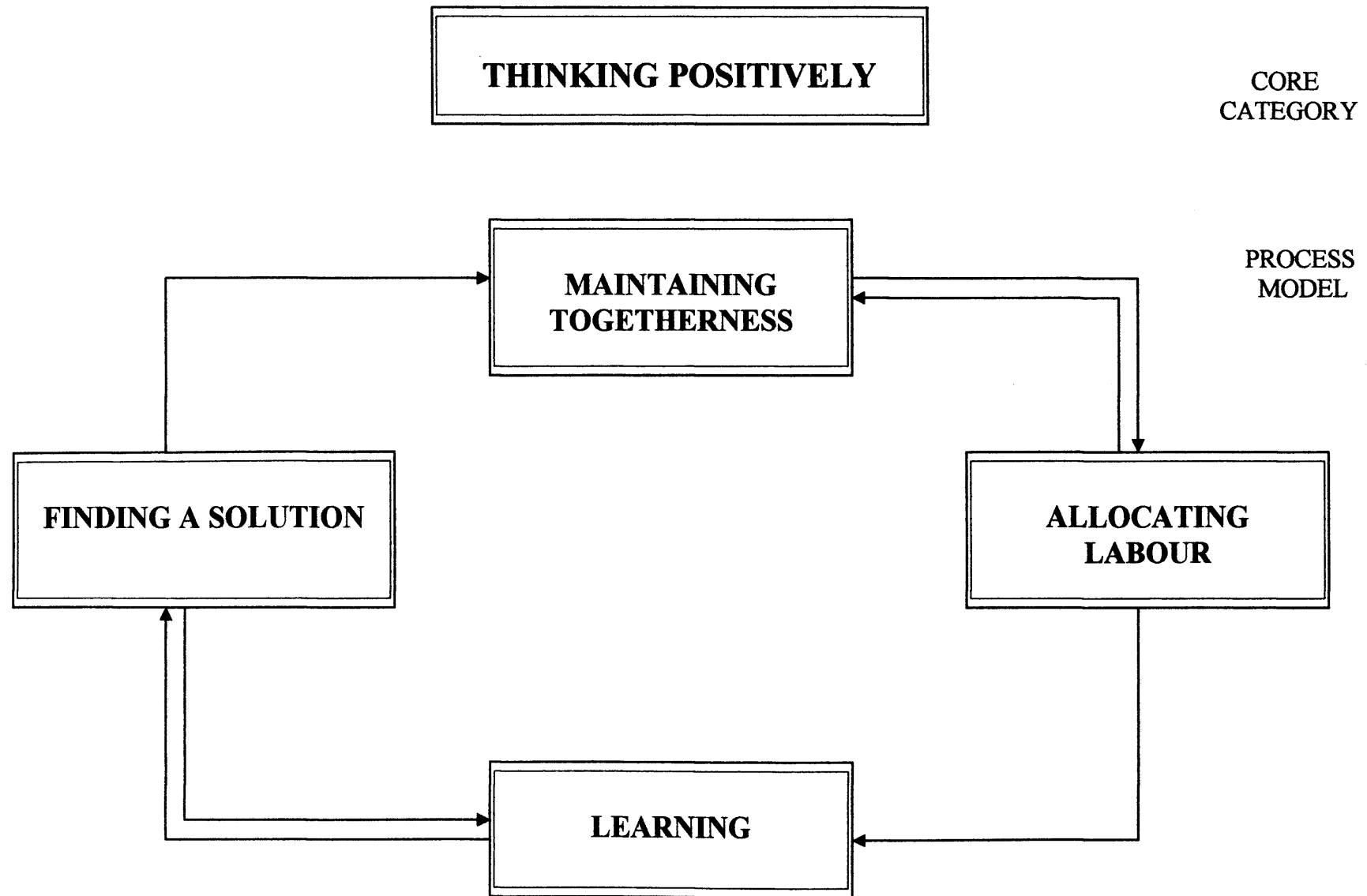
The core category identified through the analysis was termed *Thinking Positively*. It represents the primary conceptual focus of the parents' narratives and was therefore a key experience of the parents studied. Below this, four main categories emerged illustrating how parents cope. They are: *Maintaining Togetherness*, *Learning*, *Finding*

*a Solution and Allocating Labour.* An illustration of the model is provided in *Figure*

*1.* Arrows within the process represent movement among categories and returning arrows highlight the bi-directional relationship between certain categories e.g.

*Maintaining Togetherness and Allocating Labour, Learning and Finding a Solution.*

All categories are intimately connected. The model conceptualises parents' efforts at coping as fluid, highlighting a continuous, shifting and cyclic process.



**Figure 1. The core category and the process model**

### 4.3 The Core Category: Thinking Positively

The core category identified was termed *Thinking Positively*. It represents the foundation stone of the story of how parents cope and subsequently adjust to their child's brain injury. Parents felt that thinking positively was mandatory; failing to be positive was feared to have personal and catastrophic consequences.

*"You've got to be because otherwise you'd be at the bottom, you'd be in the pit yourself and life wouldn't go on" (Emily: 47, 1160-1161))*

Parents were seen to think positively in three main ways: i) *Selecting Positives from the Negative*, ii) *Being Optimistic* and iii) *Making Positive Comparisons*. Coping with their child's encephalitic brain injury was noted to be strongly guided by these cognitive orientated strategies.

In hearing that their child was brain injured, most parents felt shocked, confused and scared. After being given an accurate diagnosis and when the child was medically stable, this negative affect began to change. Parents began to concentrate on selecting the positives from the illness, typically citing the developmental abilities the child had managed to retain in the face of their encephalitic illness. Selecting and concentrating on the positives allowed parents to diminish perceptually the threat posed by



encephalitis, thereby encouraging them to see their child's adversity as a forerunner for a brighter future.

*"... if I can see something like in [son's name]'s case it was dire but (.) yeah it may be dire but you can go, you can only go on from here that's things can only get better [um] erm (.) I can take situations out like (.) you know if something happened that was bad, I can take something positive out that"*  
(Richard: 26,625-629)

Selecting and concentrating on the positives from the negative resulted in improved mood and competency, allowing parents to re-engage in practical tasks such as eliciting sources of support.

*"... I was depressed for the next three days, I was really upset, really down, I just couldn't come to grips with what's happened you know what was taking place and what had happened to him and then I actually thought about the positive side, I thought at the end of the day you know he's got some damage there but he could've ended up in a wheelchair and no quality of life at all, so I tried to think of the positive side, at least at the end of the day yes he can walk, he can talk, he has got some quality there so I started thinking positive and I felt better, and then I actually er was ringing around people, speaking to people and then I actually got the encephalitis support group which I never knew they had" (Gill: 34, 823-832)*

Taking the positives from the negative was seen as an ongoing process. Parents described a propensity to look beyond the child's negative and challenging sequelae and instead focus on appreciating the child's positive personality traits. This seemed to neutralise the threat posed by the child's post-encephalitic behaviour, allowing an enjoyable parent/child interaction to occur.

*" . . . he can be helpful [um] you know the other side of him does come out [um] he's like he wants to help me do the cooking, so like we do the cooking which nice" (Ben: 5, 105-107)*

The majority of parents commented that thinking positively involved being optimistic which was seen as maintaining a sense of confidence and hopefulness over the child's future. A repeated theme within the core category viewed thinking optimistically as mandatory rather than a choice. Adopting a non-optimistic attitude was perceived by all the parents interviewed as having a negative impact.

*"I have to be optimistic about the future because I think if I wasn't I don't think I would function to the extent that I do" (Mary: 41, 990-991)*

*"If you're not optimistic you don't cope" (Emily: 70, 1720)*

Parents felt the importance of being realistic, which involved ‘accepting’ that encephalitis had limited their children’s future.

*“I think I’m optimistic but I’m also realistic. I know she’s not going to have a job that I would have envisaged her to have” (Mary: 39, 944-945)*

All parents in the study made positive comparisons which helped them think positively. This involved comparing their child’s difficulties to other children with encephalitis or those believed to be more chronically ill.

*“I remember thinking back but my situation’s not as bad as yours, his lad had got cancer and (.) had so many operations he was er (.) is it spina bifida [um] you know, he was confined to a wheelchair” (Richard: 24, 575-578)*

Making a positive comparison seems to provide a measuring stick by which parents are able to feel better about their child. Various stressors may, to some extent, be normalised and appraised as inherently manageable against children perceived as worse off. As illustrated by the following quote, making a positive comparison appears to provide a context in which parents feel fortunate about their life and their child’s encephalitic brain injury.

*“... we always think we’re quite fortunate cos a lot of children with encephalitis are a lot more serious than [son’s name]” (Emily: 80, 1977-1978)*

Parents in the study valued the idea of talking to other parents of children who had been through and survived the acute phase of encephalitis. Being able to make a direct and positive comparison with a child who had been ill with encephalitis exposed parents to the possibility of survival, which encouraged them to think positively.

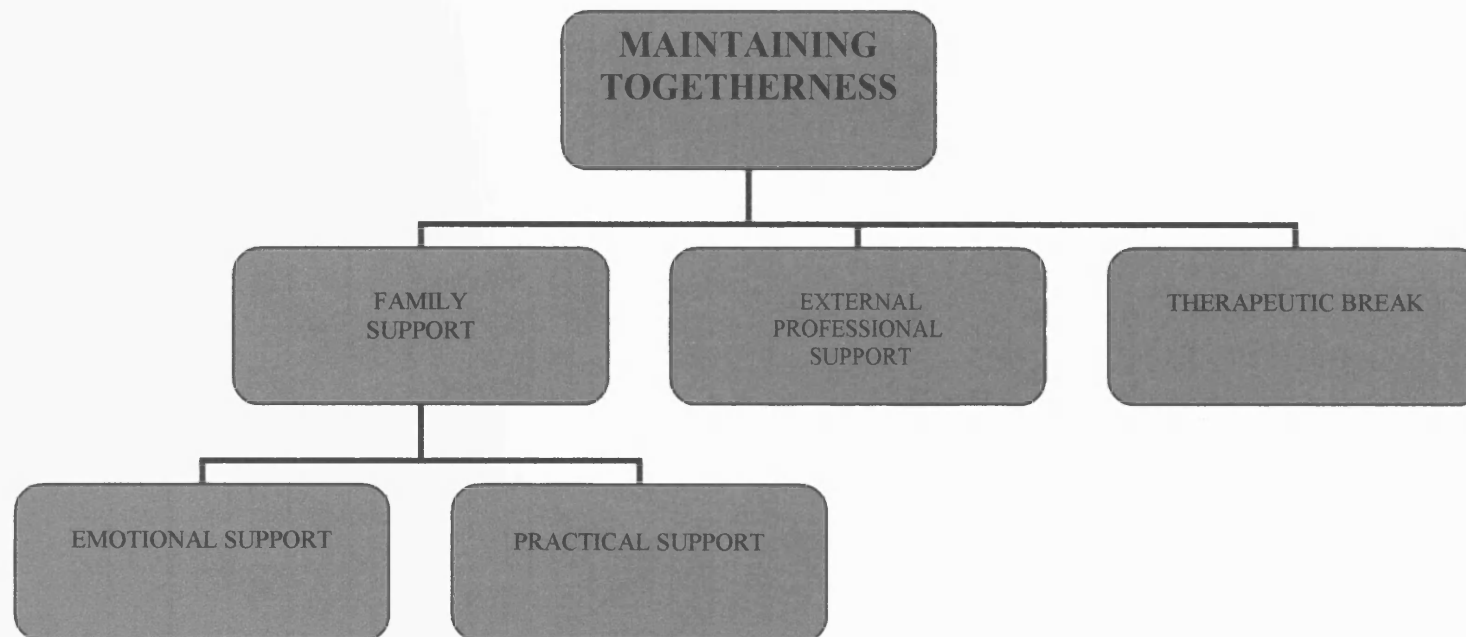
*“ . . . this girl’s parents came to chat to us so I think the fact that somebody there [um] whose daughter had already had a diagnosis and I think she’s had it a couple of years before erm and she’s actually been admitted cos her seizures were actually quite bad, I think we found that quite positive”*

*(Mary:16, 391-395)*

*Thinking Positively* as the core category encompasses several ways that parents control the meaning attached to their children’s encephalitic brain injury. Subsumed beneath this core category, a model relating to other constituent parts of parental coping has been developed.

#### **4.4. Main Category: Maintaining Togetherness**

The first main category of coping identified in the analysis was ‘*Maintaining Togetherness*’, as depicted in *Figure 2*. This category represents a process in which parents strive to contain their emotions, in part by maintaining a sense of family and spousal cohesiveness.



**Figure 2. Maintaining Togetherness**

The process of maintaining togetherness proceeds throughout the trajectory of the child's illness and recovery. Parents reported feeling emotionally together as a result of being physically together.

*"... once we was altogether we were a lot stronger emotionally as a unit"*  
(Richard: 15, 368-369)

Maintaining togetherness seemed to fulfil a defensive and protective function as it helped provide a sense of equilibrium in the face of multiple stressors, continuing the evolutionary theme of family members protecting each other. As such, being together as a family was articulated as a need by one mother.

*"I think we said as a, as a family network we needed to be together"* (Emily:  
7, 148)

The process of *Maintaining Togetherness* is represented in two intermediate-level categories termed '*Family Support*' and '*Therapeutic Break*'. The category '*Family Support*' contains two sub-categories entitled '*Emotional Support*' and '*Practical Support*'.

#### **4.4.1. Intermediate-level category: Family Support**

Giving and receiving support among family members was the ‘cement’ that helped maintain family togetherness. The study indicated different phases in providing support, a process that began when the child was acutely ill and admitted to hospital. Mothers interviewed reported the need to first support their sick child which involved being physically close at all times.

*“I lived at the hospital, I probably had two nights at home . . .” (Mary: 17, 415)*

In order to support their children, two mothers in the study seemed to guard against being distracted by other people. This could be interpreted as an act of self-preservation.

*“You don’t want intruders erm just go away” (Emily: 24, 589)*

#### **Sub-category: Emotional Support**

In this category parents reported about receiving emotional support from wider family members, including parents and older siblings. For one married couple emotional support from the child’s grandparents during the acute stage was valued less than by other mothers in the study, who, due to their relationship circumstances, relied more heavily on emotional support from their parents.

The process of receiving emotional support from grandparents started immediately from their grandchild first showing symptoms of encephalitis. It continued throughout the child's hospitalisation and beyond, being particularly valued prior to diagnosis. The married mothers in the study reported and appreciated receiving emotional support more than their spouses.

Emotional support was seen as fulfilling a number of functions, including: i) empathy; ii) the containment of distress; and iii) advocacy.

*" . . . I was cracking up and she [mother] was just there for me, she would just talk to me you know comforting me and just really she said to the nurses can they lay off her because you're telling her different things, she just doesn't know what's wrong with him" (Gill: 17, 401-404)*

Feeling emotionally supported appeared more subtly to be about resting assured in the knowledge that a source of emotional support would always be accessible to them. This seemed to offer a sense of security; however, it also promoted negative appraisal of one's own coping skills in the absence of such support.

*"They support me in the fact they'll come and have cups of tea with us and chat [um] but I think knowing that they're still there I mean God forbid if anything happens to them I don't know" (Mary: 52, 1259-1261)*



### **Sub-category: Practical Support**

The category 'practical support' refers to family members, namely grandparents, undertaking actions designed to temporarily alleviate parents of stress engendered on a daily basis by caring for their brain injured child. Parents felt that practical support was particularly useful once the child had returned home. It is at this stage that medical services typically withdraw and caring duties become the exclusive preserve of mothers and fathers.

Parents with more than one child reported finding it helpful when grandparents offered to care for siblings, thus reducing overall coping demands.

*"My parents are pretty good so in the summer my dad will get, take [son's name] off fishing and my mum will have time with [son's name] and they'll go do some baking" (Emily: 69, 1689-1691)*

All parents felt that receiving practical support from grandparents allowed them to have a break from caring duties; freeing up time to be used to replenish energies needed to continue coping.

*"... when [wife's name]'s mum takes him out for a bit and that does help. She has him on a Saturday erm well the weekend and then on a Thursday when he goes with his brothers that like gives us a little bit of a breather just just recuperate a little bit" (Ben: 12, 280-283)*

#### **4.4.2. Intermediate-level category: External Professional Support**

This category refers to parents' accounts of receiving professional support. Parents reported receiving support, albeit limited, from social workers, psychologists, paediatricians, nurses and voluntary organisations such as the Encephalitis Society. The process of receiving professional support began during the child's hospitalisation, with nurses offering informal advice and instruction that helped parents maintain family togetherness.

*"... the nurses there were bloody brilliant with him er [um] and gave us so much support too..." (Richard: 27, 658-659)*

Nurses offered guidance on eating and sleeping, as well as giving other informal advice.

*"I'd only just met him [husband] and the nurse had a chat with me and said you've got a good 'un there and he could just walk away at any time you know he don't have to deal with this he'd only just met you three weeks ago he could walk away, you've got a lot of problems at the minute..." (Gill: 18, 421-424)*

All the mothers in the study reported having received information and support from the Encephalitis Support Group, both during the child's hospitalisation and afterwards.

*" . . . that my dad got in touch with the encephalitis support group so the information was kind of coming from them [um] as we were getting ready to come home really. And then the society did actually contact me and I spoke to them a few times on the phone [laughing] best as you can." (Mary: 23, 546-550)*

Several parents had experiences where professionals would become involved in their child's case, offer short-term support and then leave. All the mothers interviewed in the study commented on the difficulty in obtaining professional support. One father reported that professionals, particularly medical staff, don't attempt to understand parent's concerns. This view was shared by the three mothers in the study, who all reported having not been listened to properly by their G.P's.

*" . . . they need to actually understand when a parent's concerned. I think there's a lot of people in medical profession that don't take you seriously until it all goes belly up . . . " (Richard: 5, 103-104)*

*“ . . . he just really wasn't himself, I took him doctors actually in a space of a week he must have went three times erm three or four times doctors erm it's a viral infection, he said er it's just a virus, give him Calpol, plenty of fluid [um] but it just er deteriorated and deteriorated, I took him back again and er it's a viral infection, carry on what you're doing” (Gill: 10, 239-243)*

#### **4.4.3 Intermediate-level category: Therapeutic Break**

This category has been defined as ‘therapeutic break’ to refer to parents needing to stop caring duties, for however short a time, in order to look after their psychological well-being. It involves taking a total break from coping with demands. This was achieved through engaging in relaxation, work and respite.

Relaxing was identified by parents as having therapeutic benefits.

*“ . . . watch tele or have a talk with [wife's name] or whatever it's like it unwinds you a bit [um] same like go to work” (Ben: 37: 899-900)*

Taking a short break, even for a matter of minutes, was felt to be obligatory particularly when managing a child's challenging behaviour. Therapeutically, parents felt it allowed them time to reappraise the stressor which subsequently changed their affect.

*"... I go outside and I just stay there for a minute even though he'll [husband] say oh you're skiving are you coming back in but just to give me a breather to think, just you know [um]lets calm down" (Gill: 51, 1245-1247)*

Both fathers and two mothers in the study reported the importance of work. Work was perceived as a distraction away from having to constantly cope, as well a source of personal validation.

*"... as soon as I get to work (.) that switches off home" (Ben: 35, 861)*

*"...trying to hold down a job so I get some sort of stimulation I suppose and have some self-esteem that I'm actually going out and earning" (Mary: 61, 1489-1490)*

All parents in the study, particularly mothers, emphasised the need for respite care as this was perceived as the ultimate goal in providing a therapeutic break, both for themselves and the child. One mother welcomed respite, irrespective of duration.

*"... even just an hour" (Emily: 3, 74)*

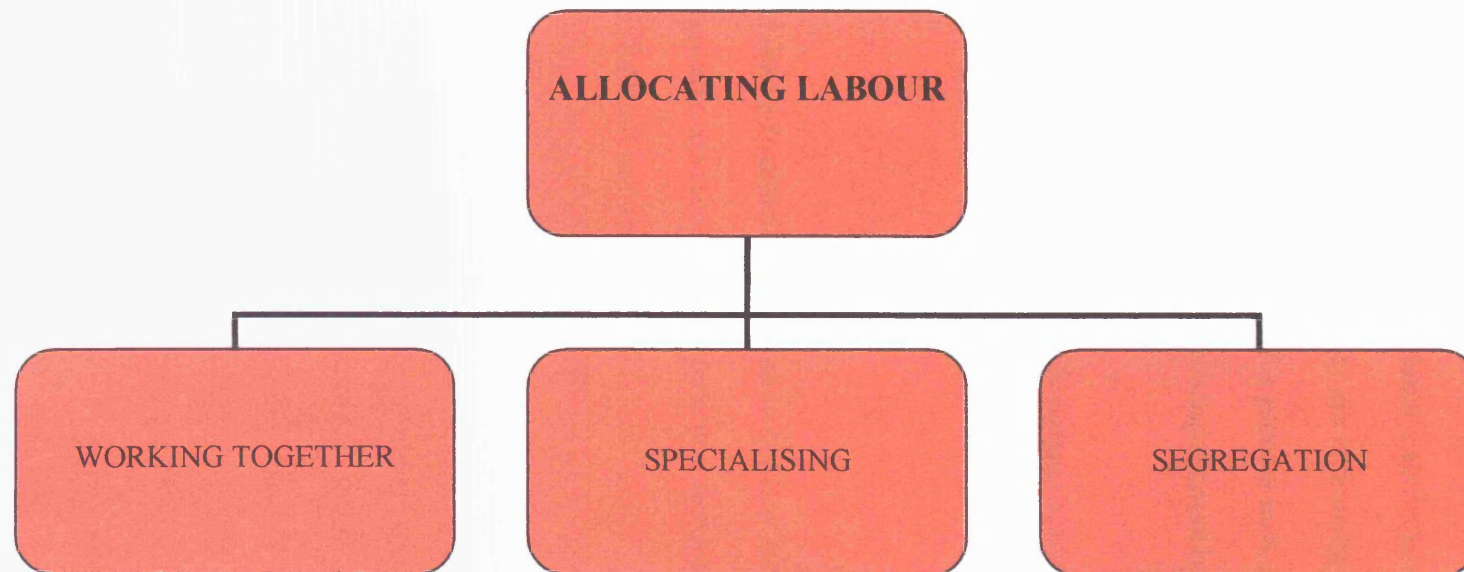
Experiencing a therapeutic break was regarded as essential, not only for parents but also siblings of the post-encephalitic child. Both of the two parent couples in the study

had other children. One mother felt respite would allow her to spend time with the siblings, helping her to promote, protect and maintain family togetherness

*“We need respite so we can spend quality time with them cos they’re the ones that are suffering” (Gill: 5, 103-104)*

#### **4.5. Main Category: Allocating Labour**

The second main category identified in the process model was termed ‘*Allocating Labour*’. The term is used to describe the process of how mothers and fathers position themselves in relation to each other in order to cope. It is inherently about gender differences and how allocated roles are prescribed and fulfilled in the household in order to care for the child, any siblings and each other. A summary of this category is shown in *Figure 3*. As can be seen, the main category is split into three intermediate level categories. These are termed ‘*Working Together*’, ‘*Specialising*’ and ‘*Segregation*’. All three categories are intimately connected and feed into one another. The process of allocating labour took on greater significance once the child had returned home from hospital.



**Figure 3. Allocating Labour**

A bi-directional relationship exists between the two processes of *'Allocating Labour'* and *'Maintaining Togetherness'* (see *Figure 1*). In order to maintain spousal and family togetherness, it appears to involve allocating labour (e.g. coping demands) successfully. This relies heavily on each parent's ability to communicate clearly and effectively with one another about how they are appraising their child's encephalitis and their feelings in relation to stress. If this process fails, family togetherness may be jeopardised, as demonstrated in the following account by a single mother.

*"I think I've pulled more towards my parents because he [ex-partner] pulled back he pulled away and just wasn't basically there really" (Mary: 29, 715-716)*

A breakdown in family togetherness appears to result in labour being disproportionately allocated to one parent only thus making the demands of coping potentially more difficult to manage.

#### **4.5.1 Intermediate-level category: Working Together**

Working together was just one way the two parent couples in the study managed the stressors engendered by caring for their brain-injured children. It involved allocating domestic demands equally through shared negotiation. Sharing demands appeared to enable coping to take place by preventing one partner becoming overwhelmed.



Parents considered successful communication was essential, as well as viewing one another as part of a team.

*"I think communication makes us stay a family and that's been hard you know. It definitely helps us work with one another" (Emily: 76, 1866-1867)*

*"... You've got to have team work otherwise it'll just go to pot" (Ben: 29, 713)*

Working together as a team was in stark contrast to the experiences reported by the single mother in the study, who said the responsibility of coping rested solely with her.

*"I just function I suppose, I don't know I just yeah I just get up erm cos I didn't there's nobody else to do it" (Mary: 51, 1252-1254)*

The two married mothers in the study felt that working together involved monitoring and being tuned into their husbands' psychological well-being and vice versa. One mother reported this meant looking after each other and working to galvanise one another in continuing to cope when demands became overly taxing.

*"We'll pick each other up at that stage" (Gill, 49: 1201)*

*"I think we were very supportive and worked together. I think out of the whole experience we most probably had two disagreements" (Emily: 38, 935-936)*

#### 4.5.2 Intermediate-level category: Specialising

Specialising refers to parents' reports that caring duties are generally balanced equally but each parent has a particular role they fulfil more than others (e.g. they specialise). This role relates to activities aimed at managing certain coping demands. Specialising was particularly dominant in the narratives of the parental couples. However, all the mothers in the study reported specialising more than their partners in solving problems relating to their child's welfare. This involved either attempting to find solutions or seeking out others who could help provide answers to medical, behavioural, social and educational stressors.

*"It's the care, it's the pastoral support, it's the liaising with health, liaising with education, it's writing reports and co-ordinating things" (Mary: 45, 1102-1103)*

*"... she's [wife's name] like the organiser of the house" (Ben: 17, 414)*

One mother felt better equipped than her husband to engage in problem-solving both in terms of having time and resources, for example, having easy access to a telephone. This mother held the belief that women were generally better at multi-tasking than men and that: *"90% of the time we're [mothers] on hand" (Emily: 60, 1468)*. She

reported that specialising for her involved ‘doing it all’ and that this provided a sense of mastery.

*“I do it all but not because he doesn’t want to do it. I’m a bit of a control freak. If there’s appointments to sort, I sort, there’s phone calls to be made, I make (.) there’s disability forms to be done I go and sort them (.) it’s having control” (Emily: 58, 1434-1436)*

When asked by their partners, husbands would undertake some of the tasks in the quote above, although their wives would often have to ‘tie up loose ends’. Generally, the two fathers appeared not to specialise in any one area, perhaps due to their wives dominance in taking on specific labour demands. They reported offering their partners practical support around the home which seemed to help mothers to cope emotionally, bolstering their ability to continue specialising. In particular, fathers talked about spending time on child care and engaging in activities of daily such as cooking and cleaning. This provided mothers with some respite and diminished overall coping demands.

*“... I’ll help her out with looking after the kids [um] you know give her that bit of support so she’s not on her own” (Ben: 20, 491-492)*

There was a clear and negative consequence of specialising for one married couple. The father reported feeling neglected and pushed to the periphery of the child-parent

sub-system due his wife assuming a disproportionate amount of labour. In return, she acknowledged that her efforts in specialising could lead to others being excluded.

*“I need to do things as well because (.) you know I’m his dad [um] er and I need to be involved because if you keep me out of it [um] for long enough then I won’t know (.) what pressures or what worries or whatever it is that’s going off” (Richard: 35, 857-859)*

*“I definitely do forget and I get so in this controlled way that I’m doing this, this and this where anybody else around is not (.) in that equation at all” (Emily: 74, 1821-1823).*

#### **4.5.3 Intermediate-level category: Segregation**

Segregation was the term used to describe the pattern of allocating labour that was forced upon the single mother in this study due to the break-up of her relationship with her former partner. It was unclear how long she had been single, although it appeared from various comments that her relationship broke down due to their child’s encephalitis. All parents in the study reported finding it difficult to maintain a spousal relationship in the aftermath of their child’s encephalitis.

Segregation refers to the single mother’s experiences of having to undertake ‘all’ the coping demands engendered by her child’s encephalitic brain injury. Some of her caring duties have been outlined previously under the category ‘*Specialising*’. Unlike the married mothers, she had no choice in specialising – she felt it to be enforced.

As a consequence of the segregation pattern, this single mother reported having to find alternative ‘working together’ relationships in order to allocate coping demands. She said this including her gaining practical support from her parents; but the main allocation of labour still rested on her shoulders.

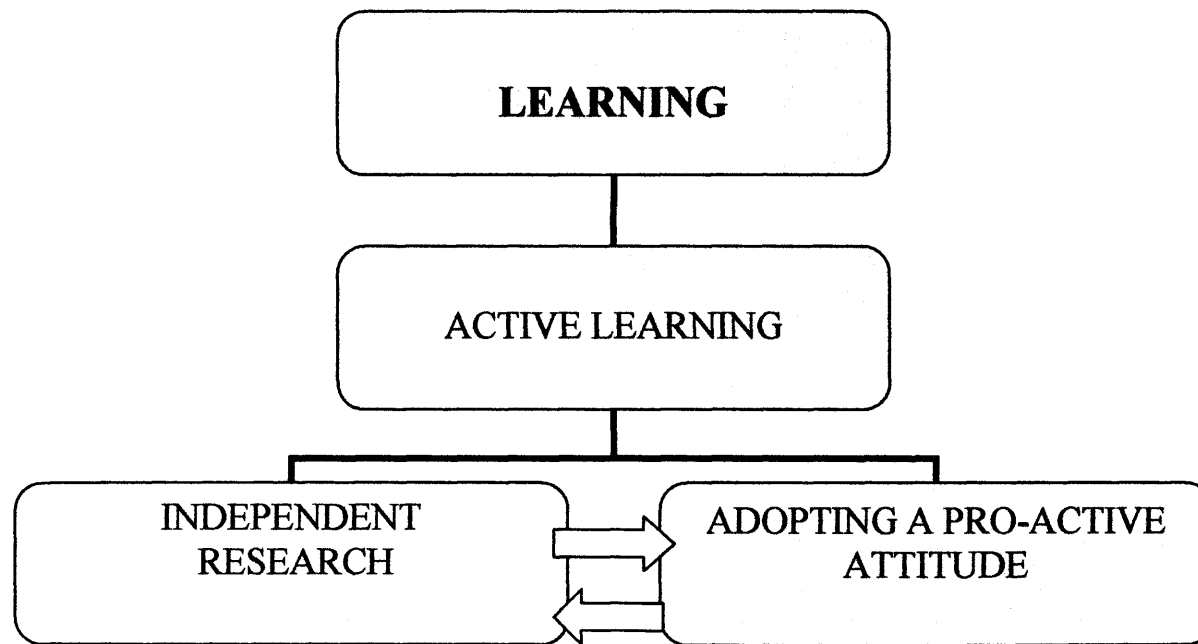
It appeared from her account that being a single mother with sole allocation of labour resulted in a conflict of roles, perpetuated in part by the ongoing demands of her child’s rehabilitation.

*“... there’s gonna come a point where I just want to get back to being a mum rather than a case manager” (Mary: 58, 1419-1421).*

#### **4.6 Main Category: Learning**

The next main category identified in the process model was termed ‘*Learning*’. Here, as a response to their child’s illness, parents engaged in a learning process which involved acquiring knowledge about encephalitis and brain injury through a variety of modes. The majority of parents experienced learning as an unavoidable consequence of the children’s illness: they felt acquiring knowledge enabled them to cope better.

*Figure 4* provides a summary of the categories. As can be seen from *Figure 4*, one intermediate-level category termed ‘*Active Learning*’ is depicted, comprising two sub-categories: ‘*Independent Research*’ and ‘*Adopting Pro-active Attitude*’.



**Figure 4. Learning**

#### **4.6.1. Intermediate-level category: Active Learning**

Following their children's admission into hospital, parents were forced into becoming passive recipients of medical information. For some parents this information was complex, sometimes contradictory, inadequate and occasionally lacking in usefulness. Parents' passivity, combined with information they had already received, engendered in them a need to know more. The term '*Active Learning*' refers to a process whereby parents as 'learners' are engaged in a learning process that is about 'doing' rather than absorbing information passively. Alongside information gathering, parents had to actively learn how to relate to a child with a host of difficulties. It seemed that all parents were invested in all phases of learning.

The majority said that encountering encephalitis forced them into a position of having to accumulate new knowledge. Active learning was felt to be a process that they 'had' to opt into.

*"It's educating erm I don't think you have a choice really" (Emily: 11, 262)*

Most parents felt that active learning began very early on in the trajectory of the child's illness. In part, this was a functional response to receiving insufficient information about encephalitis from healthcare professionals.

*"The nurses were really supportive but in terms of giving us information on encephalitis and brain injury [um] possibly not because I don't think they'd particularly come across it before" (Mary: 19, 462-464)*

Learning was considered by parents to be an ongoing process. Experience taught them how to cope.

*“ . . . I’m feeling like sort of learning how to cope with it [um] you know how to deal with [son’s name]’s [um] you know I didn’t know how to cope with it at start” (Ben: 40, 976-978)*

The majority of parents mentioned that one of the outcomes of active learning was that it allowed them to understand encephalitis which consequently enabled them to better support themselves and their child.

*“To understand and comprehend the difficulties [child’s name] has [um] and to try and help her through it” (Mary: 58, 1411-1412)*

### **Sub-level Category: Independent Research**

All parents described undertaking research into their child’s encephalitis independently of help from healthcare professionals. Indeed, information on encephalitis from professionals was often felt to be minimal or not forthcoming at all during the acute stage, thus forcing parents to self-educate. As such, research began for some parents when the child was in hospital. Undertaking research involved



using a variety of modes to look for information including the use of modern technologies and the media.

*"... the consultants are telling you things and er it was ood day when I come home and pick up mail after dropping [son's name] off at school and I'd go on the internet [um] and found its microplasma" (Richard: 6, 133-135)*

*"I've read books and got stuff from internet and emailed various people you know that know stuff like that can help" (Gill: 47, 1145-1146)*

Engaging in independent research also led to parents choosing to watch relevant television programmes they regarded as a source of education. In particular, medical programmes provided parents with a context in which to evaluate their child's difficulties. It seemed that through identifying with media images, parents gained a sense of optimism about their child's future, which subsequently triggered them into action. For one mother this meant pursuing the possibility of appropriate treatment that would benefit her child.

*"I'll purposely watch documentaries on TV about all sort of medical programmes and conditions and sit and watch them and where things you know real life factual programmes where things look really dire and then at the end of it the outcome's been fairly positive so I think when you see real life people that have gone through I mean Christopher Reeve OK it was*

*completely different [um] but you look at what he achieved but you look at what he achieved and from that I think well you know with the right help and support there's something there, there's something [um] that can be done"*  
(Mary: 54, 1331-1338)

*"... all of a sudden we hear Botox could actually calm some of the muscles down and we're straight to the hospital erm we got that from watching a programme" (Emily: 11, 259-260)*

Watching relevant television programmes helped one father understand where he was in terms the adjustment process, and where he might aspire to be in the future.

*"I'll watch programmes I think can help us you know, I mean there was a programme about port marks recently [um] and I remember watching that and er there was one woman she well so what I'm not bothered you know if they want to look that's fair enough I'm still it's still me it doesn't bother me. We might get to that stage but at the moment I still think it's quite touchy"*  
(Richard: 53, 1290-1294)

### **Sub-level Category: Adopting a Pro-active Attitude**

A pro-active attitude was felt by parents to be essential in order to learn effectively. This was particularly enabling and beneficial when parents were liaising with

professionals and struggling to convince the Local Education Authority (LEA) of their children's special needs.

Most parents felt that because information was not freely available, there was a need to pro-actively seek it out.

*"... you just find it for yourself [um] you know don't come to you for it [um] you've got to go to them [um] you've got to just find where to start" (Ben: 47, 1141-1142)*

*"... if I didn't go out and find that information and ask for it to come it wouldn't drop on my doorstep" (Mary: 59, 1452-1453)*

One mother believed passionately that being pro-active involved asking questions. She felt that other parents should never be afraid to seek out answers.

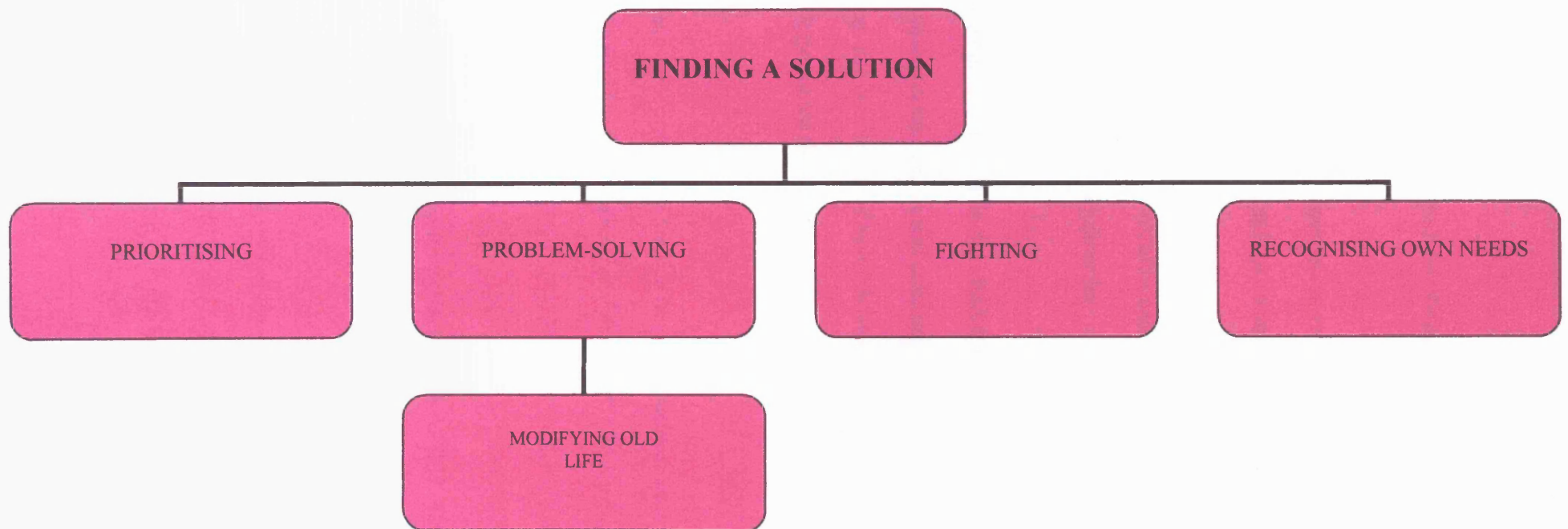
*"... I didn't get the answer from his speech therapist so I went higher and I didn't get the answer from her so I went higher. Don't ever be afraid" (Emily: 79: 1941-1942)*

*"I think because over the years I mean I do try and attend seminars which the Encephalitis Group put on [um] or the Children's Brain Injury Trust and I've attended various things over the years erm two and one day seminars, erm and I've tried to find out as much as I can to give me the knowledge that I need to try and get what's right for [child's name]" (Mary: 55, 1349-1353)*

As illustrated in *Figure 4*, a reciprocal relationship exists between the categories 'Independent Research' and 'Adopting a Pro-active Attitude'. Adopting a pro-active mindset was important as it provided the necessary impetus to ask questions and engage in independent research. Seeking out information on encephalitis and its management produced knowledge which helped parents to feel empowered, feeding back into maintaining a pro-active attitude.

#### **4.7 Main Category: Finding a Solution**

The final main category of the process model was termed '*Finding a Solution*'. This category represents parents' attempts to manage, master or find a solution to some of the multiple stressors engendered by their child's encephalitic brain injury. As a process, it is inherently cognitive-behavioural in nature. The category is illustrated in *Figure 5*. It comprises four intermediate-level categories. These are: '*Prioritising*', '*Problem-Solving*', '*Fighting*' and '*Recognising own Needs*'. The category '*Problem-Solving*' encompasses a sub-category labelled '*Modifying Old Life*'.



**Figure 5. Finding a Solution**

#### 4.7.1. Intermediate-level Category: Prioritising

*Prioritising* was described as a re-organisation strategy that parents used to manage multiple and competing coping demands. As a strategy, parents felt that prioritising prevented them from becoming overwhelmed. *Prioritising* was particularly important when parents had other children to look after and work commitments to juggle. It seemed to allow parents to impose some order.

Parents often started prioritising when the child was critically ill in hospital. This involved placing value on that which was prioritised as most important at that particular time (e.g. life over death). Once this assumptive value was validated by the child's recovery, it promoted faith in their being able to cope with anything thereafter.

*"... the main priority was as long as he can breathe er that was the big thing, that was the big thing and nothing else mattered" (Richard: 13, 319-320)*

The majority of parents experienced prioritising to be incredibly effortful. Despite this, placing the child first was seen as obligatory.

*"I'm having to run in and out during the washing, run in and out during the dinner and everything else, you've got to put him first erm and be with him constantly all the time" (Gill: 6, 147-149)*

Prioritising entailed parents having to accept the consequences of their child's brain injury while at the same time modifying their own previously held parental aspirations.

*"In terms of work and all of that I I really I am not bothered. I mean she loves animals, she loves being outdoors I mean for like you know I says she can go and bloody work on the local farm planting potato seeds, I mean she would absolutely love that bit it would be meaningful to her and that's the main thing" (Mary:40/1, 983-987)*

#### **4.7.2. Intermediate-level Category: Problem-Solving**

Problem-solving appeared to take on central importance after the child had returned home when parents - primarily mothers - struggled to solve the problem of accessing appropriate healthcare services for their children. The biggest antagonists seemed to be the LEA and Social Services. Finding a way of best managing their children's sequelae also posed a problem for parents. Increased or shared mastery over the stressor and a reduction in feelings of worry, apprehension and conflict were two outcomes of successful problem-solving. Parents commented on the need to be tenacious and creative in order to solve problems.

The experience of solving problems was an ongoing experience for most parents.

*"I think we have to problem-solve constantly" (Emily: 42, 1030)*

From their narratives, it appeared that successful problem-solving involved parents eliciting the involvement and support of professionals. This helped in having a wider repertoire of possible solutions to choose from.

*“... because I was making phone calls to the County Hall constantly erm we ended up with a very good Ed Psych who came up with loads of ideas” (Mary: 5, 119-121)*

All parents felt that problem-solving required flexibility as they constantly had to reappraise and modify their thinking and behaviour in relation to solving a problem.

*“... rather than (.) shouting about it and raving at [son’s name][um] cos we know it’s not gonna get anywhere with him [um] because he’s not registering he’s not doing it so we had to think of something else and we thought well go up there rather than keep shouting at him [um] we take him upstairs...”*  
(Ben: 42, 1019-1022)

### **Sub-category: Modifying Old Life**

The majority of parents reported having to modify their old lives in order to accommodate their child’s brain injury and special needs. They had to make sacrifices in terms of changing work patterns as well as more practical considerations. Such



changes were aimed at minimising the impact of stressors arising from their child's brain injury, thus fostering an environment conducive to adjustment.

*"I think cos literally I gave up work and spent four years and I was just constantly with her twenty-four seven . . ." (Mary: 29, 695-696)*

*"It was things like [son's name] had a bunk bed. Well, he came home and he couldn't have bunk beds erm so we came home and modified the bedroom one afternoon to make sure his room was there [um] and there was a bed" (Emily: 41, 1016-1018)*

#### **4.7.3. Intermediate-level Category: Fighting**

This intermediate category represented parents having to adopt a fighting spirit in seeking out solutions to benefit their child's well-being. 'Fighting' was seen as obligatory; the experience of their child's brain injury posed multiple battles for parents. All five parents in the study reported having to fight. Parents commented that they had to start fighting from the acute stage of the child's illness, but particularly during the rehabilitation phase at home. Battles were fought with medical and healthcare professionals but primarily with social services and the Local Education Authority (LEA).

The majority of parents commented that fighting for resources and support on behalf of their children was emotionally difficult and an ongoing experience.

*"... I feel like I'm just banging my head against a brick wall I'm fighting all the time for him, I've been fighting for years and I'm still sort of fighting now"*  
(Gill: 39, 950-952)

Most parents articulated that fighting was concerned with getting the correct provision for their child

*"... it's fighting for what's right" (Richard: 49, 1196)*

Parents felt that finding solutions would not have been forthcoming had they not endeavoured to fight.

*"... if I hadn't have fought or pushed to to get things we've got for [child's name] she wouldn't have a statement of twenty-five hours" (Mary: 60, 1455-1456)*

One mother in the study commented that she was forewarned by other parents in similar situations about the need to fight.

*"We were told we'd have to fight for everything. We were told that at [name of hospital] by a parent" (Emily: 49, 1198-1199)*

#### 4.7.4 Intermediate-level Category: Recognising own Needs

The category '*Recognising own Needs*' represented parents reflecting on their situation in order to identify their psychological needs. Parents, upon recognising their own requirements, engaged in purposeful action that led to these needs being met, thereby encouraging self-efficacy. All five parents recognised various personal needs including: i) the need to remain controlled ii) the need to feel useful, iii) the need to be part of a 'spousal/family system' and iv) the need to de-stress.

Parents were aware of their own needs from an early stage in the child's illness trajectory.

*"... I would be up at five and I had to go and sit by the bed. He wasn't awake, he was in a coma [um] but that was my need" (Emily: 38, 941-943)*

The single mother in the study articulated having always to consider her child before acting upon her own desires. Needing to be realistic was important and this view was shared with other parents in the study.

*"I've got to the point where you kind of want something that you want money [um] and you want something a little more challenging but equally it's gotta tie in with your own circumstances..." (Mary: 7, 168-170)*

Recognising and acting upon their needs was essential in allowing parents to look after their own mental health, particularly their self-esteem. Regarding long-term benefit, it enabled them to maintain a sense of proneness and motivation to seek out finding solutions to their child's health-related stressors.

Figure 1 shows a two-way relationship between the category '*Finding a Solution*' and '*Learning*'. Finding a solution involves parents putting into practice what they have actively learnt from various sources. Reciprocally, finding a solution, or failing to find one, represents a 'learning experience' that parents reflect on and use when attempting to problem-solve in the future. The two processes are inextricably linked.

## **5.0 DISCUSSION**

### **5.1 Interpretation of the model**

As illustrated in *Figure 1*, the core category reflects parents' cognitive attempts to cope both in the short- and long-term following the child's acute encephalitic illness. It is inherently concerned with how parents choose to appraise and evaluate their child's brain injury. This is paramount and linked to the process model in terms of initiating the procedure of executing a coping response. Thinking positively also serves to maintain positive coping behaviour and thus can be seen to radiate down, permeating the four main categories subsumed below. The core category is seen as a higher order category than the process model, which is more concerned with the practical, systemic, interpersonal and social components of how parents cope.

Placing the model within a theoretical context represents coping not as a static or unitary process but rather a dynamic, ever-changing and unfolding process. Parents' coping behaviours were seen to comprise a combination of cognitive and behavioural strategies, alongside social support - albeit instrumental and emotional - all hypothesised to be operating within a number of mutually reciprocal and bi-directional transactions (Lazarus & Folkman, 1984). This fits with the popular notion that a bi-directional relationship exist between chronically ill children and their parents in the recovery process (Taylor & Stancin, 2003).

## **5.2 How do parents cope with paediatric encephalitic brain injury?**

Interestingly, parents used emotion-focused coping strategies on a relatively stable basis. Emotion-focused coping is particularly important when health related problems have to be endured (Lazarus, 1966) as is the case with encephalitic brain injury. All five parents interviewed controlled the meaning of their child's illness by 'cognitively reappraising' it in the light of having to deal with challenging sequelae; they did this, in part, by making positive comparisons with others. Parents were then able to move forward and engage in more problem-focused strategies involving seeking out information and advice which assisted them in finding further solutions to their stress.

The function of parents using emotion-focused strategies such as 'selecting the positives from the negative' was that it gave a perception of control which enhanced mastery and encouraged parents to remain optimistic about their child's future. This then reciprocally fuelled a 'fighting spirit' and a pro-active attitude, both previously identified as helpful states in maintaining positive coping behaviour (Heary *et al.* 2003). Emotion-focused strategies aimed at altering the perception of the situation like this have been shown to be the most common strategy used by parents of brain injured children (Benn & McColl, 2004).

The majority of parents in this study talked about the difficulties but importance of needing to maintain a sense of family togetherness. This is congruent with previous research that families who successfully adapt and cope are those who are intact and

more cohesive (Minnes *et al.* 2000; Holohan & Patterson, 1991). The inclusion of the single mother in the study reflects the sad fact that many families break-up following paediatric brain injury (Harris *et al.* 1989). Analysis indicated that some parents in the current study received conflicting medical advice about their child's encephalitis, both from their G.P and hospital staff. This has important implications as research has shown that contradictory medical advice delays parental acceptance and adjustment (Ylvisaker, 1998). This is a worrying situation, as parents in a previous study commented that professional information about their child's illness was more important to them than emotional support (Baxter, 1986).

All five parents interviewed reported a struggle to find appropriate social resources which could offer them practical support, both in terms of respite and information regarding methods of dealing with problems e.g. educational and behavioural. This appeared to be an ongoing situation. Data extracted from the interviews showed that social support seeking had not declined, irrespective of the child being many years post-acute diagnosis. This perhaps reflects the unrelenting challenges posed by acquiring a brain injury during the maturation process. Receiving practical support is essential and has been shown in previous research to be positively related to emotion-focused coping in parents (Benn & McColl, 2004; Heninen & Kyngas, 1998).

### **5.3 Are there any gender differences in coping?**

The three mothers and two fathers in the study appeared to cognitively appraise their children's encephalitic brain injury equally: all parents choosing to select the positives

from the negative. All those interviewed mobilised both emotion-focused and problem-focused coping strategies, although it appeared the latter were more prevalent and had increased with time. Why was this? It could be argued that parents had reached a stage in their children's illness trajectory where they had lived with unrelenting stressors for a long-time; therefore the emphasis was on finding solutions to actively help their child adjust. Children were between 3-7 years post-onset of encephalitis when parents were interviewed. Similar findings pertaining to parents of children recovering from brain tumours have also been found (Vance *et al.* 2004).

It was clear from the study that the mothers took on more coping demands than the two fathers interviewed, supporting previous findings that mothers as the primary caregiver typically assume a disproportionate amount of caregiving (Waaland and Raines, 1991). Data extracted from the interviews provided possible reasons for this, including social and cultural expectations that mothers, by virtue of being women, should 'do it all'. Congruent with previous research into parental coping (Heary *et al.* 2003), mothers in the current study felt coping was a necessity rather than a choice. It could also be argued that assuming the 'lion's share' of coping was about needing a sense of control, allowing mothers to emotionally cope more effectively. It is interesting to note that Benn & McColl (2004) investigated parental coping with acquired brain injury and found that mothers had more extensive coping repertoires than fathers and this may explain the differences in allocated labour between genders in the current study.

A clear implication of mothers assuming too much caregiving responsibility is that their action can lead to a segregated pattern of allocated labour within the home.



Fathers can feel excluded from the parent sub-system. For example, 'Ben' spoke about his need as a father to be involved in the care of his child in order to understand and share the pressures of coping. As Gottman (1993) discussed, disproportionate caregiving by the mother can lead to poor maternal mental health and the potential for marital dissolution and family break-up. The experiences of the single mother documented in this study highlight the ramifications of having to cope without a partner.

Gender differences in coping were demonstrated by the three mothers appearing to use more problem-focused coping strategies than fathers. This was obligatory rather than a choice for the single mother in the study. Lazarus and Folkman (1984) stated that problem-focused strategies are aimed at altering external sources of stress or diluting its effects.

In the category '*Allocating Labour*', mothers were seen to '*specialise*' to a greater extent than fathers in helping their children adjust to their difficulties by engaging in practical activities akin to adopting a *solution-focused approach*. This included planning and taking direct action in seeking out respite and social support, appropriate school provision and liaising with medical and healthcare professionals.

Borrowing from the literature, the above findings contradict the popular notion that women generally use less problem-focused coping strategies than men (Vingerhoets & Van Heck, 1990). However, given that the married mothers undertook the majority of coping demands, it seems logical that they would come across problems whose content automatically required them to select more problem-focused strategies than

their spouses. In this case, it is less about gender and more about the content of problems (e.g. returning to school, searching for respite etc) arising, partly, from the child's position on the illness trajectory. Findings congruent to these have been found by Porter and Stone (1995).

All five parents interviewed belonged to the Encephalitis Society, although it was largely the mothers who took on the role of communicating with the Society and other voluntary agencies; this appeared to fulfil the need for social support in terms of getting information and advice. In contrast, the mothers sought out social support for emotional reasons more than the two fathers. For this purpose, the mothers relied upon their own parents, as well as their spouses, for moral guidance, advice and empathy. Using emotion-focused strategies to express emotion in this way has previously been reported by Pearlin and Schooler (1978), who stated that receiving emotional social support allows people to vent their insecurities and fosters a return to problem-focused coping. Furthermore, Bregman (1980) reported that seeking out social support and engaging in problem-focused coping are predictors of whether parents adjust to their children's chronic illness.

#### **5.4 Clinical implications**

During the hospitalisation of their child, parents identified needing information on encephalitis and its consequences. This was sometimes not forthcoming or confusing. Parents subsequently started to seek out information independently. As such, it is

suggested that medical staff should be taught by clinical psychologists that giving parents accurate information on encephalitis is as important as offering emotional support as it encourages parents to (i) accept their child's illness and (ii) galvanises them into using problem-focused coping strategies. Practitioners could also provide information to parents regarding which websites they recommend as useful in finding out further information on encephalitic brain injury and its management.

The results of this study indicate that parents would benefit from more practical social support resources in helping them to cope emotionally, thus aiding positive adjustment to their children's encephalitic brain injury. For example, parents reported receiving limited respite care and minimal practical advice on how to go about seeking appropriate educational input or how to obtain an educational statement.

One way of helping parents is to provide them during the acute stage of their children's illness with a clear signposting protocol of appropriate services willing to offer practical assistance. Given that those parents interviewed continually engaged in help-seeking behaviour, experienced and appropriate practical support should be offered over an extended period as the child goes through the maturational process. Long-term monitoring, assessment and support could be offered, with the object of enabling positive coping of both the child and their family. Conversely, there is a role for clinical psychologists to engage in consultancy work, thus educating services about the needs of parents and illustrating how they can cope positively. To this aim, the Encephalitis Society could draw upon the current analysis and interview data to inform training programmes directed at helping mothers and fathers cope effectively.

It is suggested that this could involve the making of parenting videos that can easily be accessed by parents and kept as a practical resource.

A more systematic method of providing practical help would be to establish community rehabilitation services, comprising an interdisciplinary team approach. According to the British Psychological Society and its paper 'Services for Children with Acquired Brain Damage' (2004), one option is to establish a community tertiary service that crosses health districts, education authorities and social services. The team should include a psychologist and, importantly, a social worker, among other clinicians who typically work with brain injured children. The lack of support services suggests professionals neglect the social context of paediatric brain injury. As such, it would be important for community services to work within a biopsychosocial model. This would involve taking a holistic approach to healthcare delivery, and one that respects the transactional and bi-directional nature of how parents cope, as demonstrated in the current research.

Further clinical implications of the current research, specifically for clinical psychologists, include offering parents training on how to make positive appraisals and work within a solution-focused approach. Alongside this, clinical psychologists could work systemically, offering psychological therapy aimed at helping parents and siblings to maintain family togetherness/cohesion.

## **5.5. Limitations of the study**

The current research involved a small sample ( $n = 5$ ) of white, working class parents living in the Midlands. The very small number of potential parents supports the epidemiological evidence that viral encephalitis is rare (Davison *et al.*, 2003).

Although paternal coping was represented by the inclusion of two fathers in the study, more mothers and fathers generally would need to be interviewed in order for the findings to be generalizable.

A potential bias in the research was the selection of parents from a pre-selected group e.g. the Encephalitis Society. Interviewees opted into the study voluntarily; it is likely that these parents represented a more motivated group of parents, but there may be others who had not joined the Society and who had found alternative ways of coping.

Due to practical constraints, theoretical sampling was not used to recruit participants and parents were not re-interviewed during the process of analysis. Variation in the sample was represented by the experiences of the single mother. It was hoped that her ex-partner, whom she described as 'not coping', may have participated in the research, allowing for a possible 'negative case' to be integrated into the analysis. As such, the model developed in this study did not contain as much variation, diversity or richness as would have been possible had theoretical sampling been conducted.

Saturation of categories was not reached in this study. It was transparent that five parents were not enough for saturation to occur. Saturation typically happens after the analysis of between five to ten cases (Rennie *et al.*, 1988). In not reaching saturation,

the conceptual depth of some of the categories was weak. Further recruitment and interviews with parents into coping would need to be conducted in order to confirm saturation for this group.

## **5.6 Ideas for future research**

Grounded theory, as a methodological tool, facilitated the current analysis. This enabled a detailed exploration of parental coping with paediatric encephalitic brain injury, both within and across individual narratives. The findings of this study support the use and appropriateness of qualitative methodologies in exploring the ‘lived’ experiences of parents coping with chronic illness in children. Ideas for further research include revisions and amendments of the current study, and new investigations arising from specific categories generated from the developed model.

Future research should include a larger number of mothers and fathers to enable saturation of categories. Re-interviewing the parents could also help expand the conceptual depth of the analysis, allowing parents to explore issues they felt unable to discuss on first meeting.

The present study should also be extended beyond the current sample frame to incorporate parents from different socio-economic backgrounds, as well as the coping experiences of siblings and grandparents. Furthermore, assessments, whether qualitative or quantitative, could be conducted at regular intervals as part of a longitudinal study to explore how parental coping shifts in accordance with where the

child is in the illness trajectory. In addition, this research could also include, wherever possible, interviews with the children themselves. Given the systemic impact of paediatric brain injury (Kazak, 1986), it would be fruitful to also explore how siblings cope and adjust to their brain injured brother or sister.

A number of categories within the developed model could be used to guide future research. The ways in which mothers and fathers re-align themselves - or not - in terms of allocating domestic labour in an effort to cope would expand upon the findings of this study. Towards this purpose, interviewing parents 'together' could show how coping relationships, albeit complementary or otherwise, are negotiated and enacted. Addressing familial communication, coping and role definition in this way is particularly important given the evidence of parents who separate or divorce following paediatric brain injury (Harris *et al.* 1989; Tew *et al.* 1974; Waaland and Raine, 1991). Finally, the role of emerging technologies as a learning tool and their impact on parenting, education and support in helping mothers and fathers to cope could most usefully be explored.

## **6.0 Conclusion**

The present study has provided a valuable insight into how mothers and fathers cope with paediatric encephalitic brain injury. Viral encephalitis results for a number of children in chronic sequelae and unrelenting stressors for the child's parents and siblings. What emerged from the grounded theory analysis was that parents cope as best they can, drawing upon a variety of emotion-focused and problem-focused coping strategies, all inter-related and reciprocally determining each other. Mothers

appeared to take on more coping demands than fathers and engaged in more problem-focused coping than their partners. Parents expressed a need for greater social resources aimed at offering practical help. This type of social support was seen as vital in helping parents to cope emotionally and subsequently adjust to the challenges of living with paediatric acquired brain injury.



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### **Section 3**

#### **Critical Appraisal**

## **1.0. CRITICAL APPRAISAL**

### **1.1. Planning the research**

The current research was born out of my experiences as an assistant psychologist during 2000-2001 when I worked in a neurobehavioural rehabilitation unit for adults with brain injuries. I had always intended to conduct a piece of research within the field but the unexpected re-location of my supervisor at the time ensured that it never happened. Nevertheless, it was my intention to explore the idea of pre-morbid family functioning and how this relates to adjustment following brain injury. In talking to family members who visited the unit, it was clear that their relatives' injury was experienced on multiple levels. I found it strange, disappointing even, that the focus for professionals was exclusively on the injury and the resulting physical and language complications. This seemed to be at the expense of family member's needs that were rarely recognised or given attention.

When I began the clinical course in 2002, I was encouraged to start thinking about research early in training. At this stage I was still interested in pursuing the idea of pre-morbid functioning as a determinant of post-injury family functioning. It appeared logical that perhaps a quantitative approach would best suit this type of question. I conducted a literature search as a requirement of the course and wrote a review on adult brain injury and post-injury family functioning. After immersing myself in the research, it appeared rather dry and uninspiring nor did the prospect of crunching vast amounts of statistics appeal to me. Through writing this review, I discovered that in

comparison very little research had been conducted on paediatric brain acquired brain injury.

While at a conference in London on CBT for depression in 2003, I bumped into my ex-supervisor whom I had worked with as an assistant psychologist. We chatted briefly over a coffee and he flagged up various areas of neglect within the current literature on childhood brain injury. It seemed there were a dearth of qualitative research and a lack of studies examining brain injury as a consequence of infections. On returning home, I started sending emails to clinicians in the field as far as Australia in order to gather more information. I conducted a provisional search using 'Google' looking at information on infectious diseases in children. It was at this point that I learnt about encephalitis. Further searching brought up a link to the Encephalitis Society in Yorkshire.

I contacted the society and went to Malton in North Yorkshire for an informal meeting with their national co-coordinator, who was the mother of a child with encephalitic brain injury. We spent two hours talking about her experiences as a parent and the struggles she faced. She highlighted the lack of research in the area, and attempted to 'sell' the idea of doing research on encephalitis. Initially, I felt pressured by this as my ideas were still formulating. She went on to tell me that the Encephalitis Society undertakes research and co-operates with researchers; accrediting projects requesting access to people affected by encephalitis. The idea of being helped to access a sample was appealing, given all the other stresses of research that would undoubtedly confront me. After that meeting, I felt that encephalitic brain injury appeared to be an 'untapped' area. Combined with my interest in systemic

issues surrounding brain injury, I decided that I could perhaps marry the two together in some way.

## **1.2. Choosing qualitative research**

After what seemed many months of deliberations, I devised the current research question and discussed it with my supervisor at university. We both felt that parental experiences of coping with childhood illness, irrespective of aetiology, was inherently a psychological journey and one that could usefully be explored in a deeper way than would be possible through a quantitative epistemology. I started to read up on qualitative research.

In terms of selecting a methodology, I began with the research question (Silverman, 2000). I carefully considered the fact that very little qualitative research had been conducted previously on paediatric brain injury and none on encephalitis. According to Turpin *et al.* (1997) qualitative methods are useful when studying psychological phenomena not previously extensively researched. Given this, I spent time thinking about the nature of qualitative research and its emphasis, in part, on revealing meanings within human transactions and behaviour. This appeared to 'sure up' my belief that a qualitative approach would be more appropriate than a quantitative one.

I reviewed various qualitative approaches but only really considered either Grounded Theory or Interpretative Phenomenological Analysis (IPA). Grounded theory appealed to me more as it offered a pragmatic choice within an inherent structure. This was comforting because I had not previously used a qualitative methodology

before. Furthermore, I appreciated the conceptual and theory-building aspects of grounded theory as it afforded the opportunity to make one interpretation from many meanings.

It was also interesting for me to see links between my clinical work and chosen research method. During the last 18 months I have largely worked within a cognitive behavioural approach, although I have also drawn on ideas pertaining to FEP (Focused Expresssed Psychotherapy). The latter has helped me to understand and unearth the reasons why some people bottle-up their emotions in order to function more effectively. I see the process of working in this way as congruent with the way in which a researcher proceeds when using grounded theory, as both encourage the need to “dig into implicit, unstated and condensed meanings” (Charmaz, 2003: 103).

### **1.3. Epistemological stance of the researcher**

Once I had started reading about qualitative research, I was taken aback by the complexity surrounding the different epistemological stances. I found these debates interesting and engaging although somewhat confusing.

In reading an article by Madill *et al.* (2000), I came across the following quote which seemed to capture why I was confused:

“... qualitative research is not a homogenous field. There are a number of epistemological positions within which the qualitative researcher can work and many different methods of analysis” (Madill *et al.*, 2000: 2).



Three broad epistemological stances were identified in the article: realist, contextual constructionist and radical constructionist. On reflection, I feel very much at the beginning of a learning curve in terms of the epistemological debate and my own position in relation to this. I anticipate this learning curve will continue past the submission date of this thesis and into my career as a clinical psychologist.

In thinking about epistemology, I liked the link that Madill *et al.* (2000) made between critical realist and contextual constructionist approaches. This bridging relationship refers to contextualism adopting a critical realist stance in terms of grounding emergent findings in the data, while advocating that social practices, fundamental meanings and organisation can, in principle, be discovered (Parker, 1996; cited in Madill *et al.*, 2000). In line with the method advocated by Charmaz (2003), I attempted to acknowledge the parents' own understandings and context in which these understandings were situated; hence I always tried to ground them in the data. At the same time, I checked my own subjective interpretations of the data through a process of reflexivity (see section 8.9). Taken together, this suggests a flavour of critical realism combined with an acknowledgment of contextual constructionist ideas.

#### **1.4. Conducting the research**

With hindsight gaining ethical approval was quite an arduous process. Although the study passed easily and only required minor amendments, it felt a bit like entering 'no man's land'. There appeared to be a great deal of confusion initially over whether I would need to submit to ethics at all, given the fact that I intended to recruit parents

through a voluntary organisation. I argued that by doing this parents could be perceived as 'healthy volunteers' and as such only university ethical approval and that of the Encephalitis Society would be needed. After numerous conversations with a representative from the Local Research and Ethics Committee (LREC), it was advised that the study would need to be thoroughly reviewed due to the children still being recipients of NHS services.

Despite feeling relatively organised and clear in terms of submitting to ethics, I found it difficult to maintain my attention on the process as I had fallen ill with glandular fever. I was unable to do anything constructive for about a month. I had to take time off clinical placement and was unable to attend an ethics review meeting for my study. I felt extremely anxious at this time and struggled to maintain a sense of perspective. Nevertheless, I heeded my supervisor's advice about needing rest in order to tackle the ongoing research process that lay ahead. Once I had received ethical approval and submitted this as evidence to the Encephalitis Society, they acted quickly to pass it through their research committee.

Once I was feeling better, I had a second meeting with the national co-ordinator at the Encephalitis Society in Yorkshire. We discussed how to proceed in securing a sample of parents from their database. The database documented the current age of the child and the age at onset of illness, alongside details of sequelae. Ethical approval was granted for three counties within the East Midlands. An initial search of the database indicated a total of 20 parents living across the three chosen counties who fitted the inclusion criteria. Only two parent couples volunteered to participate. This caused me great concern and stress although I tried hard to contain my catastrophic thoughts.

The research was somewhat cramped in terms of being unable to locate a larger sample. Many of the reasons for this are outlined in section 2.2.1. Given the low return rate, I discussed with my supervisor the option of going back to LREC in order to extend the geographical area I was selecting from. We both agreed that this would take time and would not guarantee that further parents would respond. In hindsight, I could have advertised my study more widely by using the Society's webpage or through recruiting parents from other paediatric brain injury support groups alongside the Encephalitis Society.

Liaising with the Encephalitis Society throughout the research process was an exercise in diplomacy. They were extremely supportive and continue to be so, but I felt that I had to constantly defend and explain my study as they were uninitiated in the grounded theory method. There were two occasions when I received phone calls at home from the Society seeking advice about how to assess or treat children with encephalitic sequelae. I found this strange given my stage in professional training and these requests made me feel uncomfortable. I had to reiterate that I was unqualified to give advice. I have taken from this experience that involving stakeholders in the research can bring both positives and negatives but, above all, there is a need to establish clear boundaries about expectations.

I interviewed all the parents in their own homes. I felt nervous about conducting the first interview in case I left without securing any relevant information at all. This feeling never left me for all five interviews. When I met with the first couple and interviewed them separately, both had been drinking a bottle of wine and continued to drink throughout our time together. As a probable consequence, they were very

relaxed and lucid. In comparison, I found it difficult to relax into the interview and would often ask questions that were too broad (e.g. how do you cope?) in order to get the information I needed. This seemed an obvious question to ask but on reflection, it needed to be broken down and asked more subtly in future interviews, which I feel I achieved.

In order to develop a warm rapport with the parents I called upon my therapeutic skills. This was undoubtedly useful as all parents appeared able to share very personal thoughts and feelings. On a very human level, I found it easy to emphasise and understand their experiences. When I interviewed the second father and when he became tearful, I felt incredibly emotional in response. Indeed, after each interview, I never failed to feel emotional. I used my research diary as an outlet to document and understand these feelings more fully. In the future I would like to be better equipped to understand issues of transference and counter-transference that undoubtedly occur during interviewing.

The first few interviews appeared very lengthy, particularly those with the mothers. In part this was because I was trying to cover everything, as I thought it important to get a sense of their experiences from the beginning of the child's illness trajectory to the interview period. However, later on I learned to be more pointed in terms of what I wanted to focus upon - guided somewhat by provisional analysis. In interviewing parents immediately one after another, I obviously did not have time to transcribe and code data before conducting the next interview. I interviewed the parents in this way because it was easier for them in terms of practicalities. However, after each interview I asked for a 30 minute break. I spent this time making notes and documenting any

themes I wanted to follow up in the next interview. This felt incredibly time pressured. I therefore ensured that before meeting the second couple, interviews were transcribed and some coding completed in order to inform future questions.

On reflection, I thoroughly enjoyed the interviewing experience although I found it to be an emotional one. The second father, 'Ben', was partially deaf and often struggled to hear my questions and this may be reflected in parts of his transcript. In contrast, there were lighter moments. I recall interviewing the second mother when her young daughter was crying uncontrollably and attempting to pull down a Christmas tree - while their rather aggressive cat perceived my flat microphone to be a mouse. I had to constantly separate the cat from my recording equipment while continuing to interview amid a child's loud screams.

In terms of process, I felt that my interviewing style became more fluid and confident as the interviews progressed. However, in reviewing the transcripts, I was embarrassed to find the degree to which I interrupted the parents to make reflective statements or pithy comments. I think I had a tendency to do this because during clinical assessments there is a need to reflect back your understanding of what the interviewee is saying. In future I will make a clear distinction between my two roles: clinician and researcher.

Striking a balance between undertaking research and ongoing clinical work, as well as feeling the ongoing effects of glandular fever was, to say the least, challenging. The need to immerse myself in the data very often conflicted with my clinical work and I had to learn to compartmentalise in order to cope. I was surprised at feeling so

isolated at times but, fortunately, the support from my supervisor, family and friends helped to maintain a sense of motivation to continue.

## **1.5. Analysis and Write-up**

The process of analysis was daunting from the very beginning. I was shocked that I found it difficult to master line-by-line coding, something I had anticipated not having problems with. In part, I think I had a tendency to become analytical too soon. So, I stood back and merely asked myself what was happening in the data, what was being said etc. Once I managed this, I was able to resist the temptation of becoming overly abstract. I documented these abstract and analytical insights in the research journal.

Once I had started to focus-code the transcripts, I could see findings beginning to emerge from the data; however, it seemed a long time before any coherent structure was observable to me. I constantly had to battle with feeling that I should be making faster progress and resist the temptation to rush the analysis. I was surprised to discover that the writing of the report was easier than I imagined, in part because I had spent considerable time writing analytical notes and memos that I incorporated into my write-up.

As writing began, I felt a real need to constantly check the developing model with colleagues and supervisors working in the field. The model resonated with their clinical experience; I found this incredibly reassuring and took this to mean that I had grounded the data respectively and truthfully.

One of the later challenges of the research process was a change in the format of the thesis. The clinical course had substantially reduced the word limit in terms of final write-up, and my cohort was the first to encounter this transition. In many ways, it was not easy. There were no previous examples to learn from and a general confusion and inconsistency existed about how to structure the report. Reducing the word limit made the full reporting of the results difficult, despite the fact they are considered 'the meat' of the thesis. Thinking more positively, I acknowledge that reducing the overall word limit will perhaps make for an easier job when preparing the study for publication or presentation.

## **1.6. Enhancing Methodological Rigour**

Numerous guidelines stipulating ways of enhancing the rigour of qualitative research all consistently point to the need for incorporating credibility checks (e.g. Barbour, 2001; Elliot *et al.*, 1999). These are important in order to ensure that the developing theory makes sense to people who have no understanding of the phenomena under investigation.

Credibility checks were undertaken by comparing multiple coding of excerpts from transcripts by fellow trainee clinical psychologists; a grounded theory workshop group run by a facilitator with knowledge of grounded theory was used for this purpose. The emerging themes noted by colleagues were reassuringly congruent with those I found. The group also served to provide support and teaching input on grounded theory throughout the research process. The credibility of the analysis was

further checked by discussion with a professional working in the field in order to ascertain whether the data resonated with their considerable clinical experience.

I did not ask parents to validate the emerging analysis for accuracy for a number of reasons, including ethical concerns and time constraints. Respondent validation is a strategy not without its critics. Henwood and Pidgeon (1992) argued that respondents are acutely aware of the power differential between the researcher and themselves, this inevitably affecting their willingness to provide constructive feedback.

### **1.7. Reflexivity**

In qualitative research it is imperative from the outset to explicitly acknowledge any biases and preconceptions the researcher may hold, and to address these throughout the research process (Charmaz, 2003). As a course requirement it was necessary to write a review article on the current state of knowledge in advance of data collection. Although exposed to literature pertaining to the phenomenon under investigation, I was sensitive to the importance of ensuring this knowledge did not impose itself on the data and developing theory. Chamberlain (1999) advised that any theoretical ideas and intuitions absorbed by the researcher must be held consciously and be checked carefully for congruence with the data. In order to control this, I kept a Research Journal as a tool to aid objectivity.



## **1.8. Dissemination of findings**

From the beginning of this research I was keen that the study should be ecologically useful and therefore have a practical application. As such, I hope to publish the current study in a peer reviewed journal, as well as presenting the findings at relevant conferences. I suspect that due to the low numbers of parents interviewed, it may be an arduous job to gain acceptance by a formal publication. As an alternative, I have informally discussed with the Encephalitis Society the aim of publishing the developed model in their quarterly newsletter that goes out to all members. I have also arranged for a shortened version of the study and model to be placed on the Society's website. This is particularly relevant given that all five parents interviewed talked about using the internet. I understand that the Society's webpage gets over three-hundred 'hits' a week.

## **1.9. Learning outcomes**

As a result of conducting the current study and writing up for submission, I have developed a knowledge base pertaining to the rigours of conducting a clinically relevant piece of research. I am especially pleased that it has given me a sense of confidence in not shying away from research after I have qualified as a clinical psychologist. In particular I feel I have:

1. Developed an awareness of the necessary requirements for submitting a successful proposal to the local Research and Ethics Committee. In particular, the importance of thorough preparation and the need to 'stand outside' of my

own research in an effort to critically pre-empt likely criticisms. I feel that allocating plenty of time to this cause is essential.

2. Gained a deeper understanding of qualitative methodologies and their theoretical and epistemological underpinnings. I feel confident in being able to appraise the methodological strengths and shortcoming of the grounded theory approach. As such, I feel I would be able to use the method again with greater confidence and ease in the future.
3. Developed a comprehensive knowledge of the literature on encephalitis and an appreciation of the coping experiences of parents managing chronic illness in children. I have also developed a keener awareness of how to place research within a clinical context, particularly when thinking about how as a clinical psychologist I could possibly support parents in their coping efforts.
4. Learnt that in my role as researcher, I have a tendency to fall into 'therapist mode' when interviewing. I felt at times I was asking questions, exploring processes and containing distress as I would in a clinical interview. Although I concede this was perhaps necessary given the sensitive nature of the material parents were disclosing, it made for lengthy interviews, which on reflection could have been shorter and more pointed. Through being reflexive I amended my interviewing style, hence interviews became progressively shorter as the research went along. I now appreciate the importance of clearly delineating between my roles as researcher and clinician. Furthermore, it has triggered my

thinking about ‘process issues’ in interviewing, particularly in terms of transference and counter-transference.

5. Improved my ability to critically appraise research, both methodologically and theoretically through the process of writing the literature review. Specifically, it has sharpened my scepticism about theories of coping derived from merely quantitative standardised measures. In preparing the thesis for submission, it was necessary to write multiple drafts. I have learnt the value of being clear and parsimonious when writing, as well as the importance of keeping in mind those most likely to benefit from the research – the parents.
6. Developed an appreciation of the need to be diplomatic and keep major stakeholders (e.g. the Encephalitis Society) informed of the research process. At the same time, I now have an understanding that by virtue of conducting a piece of research, other people have a tendency to assume you are an expert in that area. I have learnt the best way of addressing this is through showing humility and being honest.
7. A greater conception of the factors that go towards successful research. These include selecting a sample through a voluntary organisation, having blocks of time allocated for writing-up and realising that each stage of the process takes twice as long as originally predicted.

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## **Appendices**

## **Appendix 1. Invitational letter from the Encephalitis Society**

**"The Encephalitis Society: Action for  
support, awareness and research**

Dear Friend

I am contacting parents of children who have or who have had an encephalitic brain injury within the general (specify area) of England who have been in contact with our organization. If for whatever reason you are not happy about being contacted in this way please let me know.

Attached are a letter and information sheet giving details of a research project that we are supporting and is in need of parents of children who have an encephalitic brain injury. If you wish to volunteer and take part you can contact the researcher direct or you can phone me first to discuss any aspects of the project.

The project has been reviewed and approved by the Encephalitis Society's Professional Advisory Panel.

With all Best Wishes

Elaine Dowell, National Coordinator  
Direct dial 01 653 604 366



## **Appendix 2. Invitational letter from the Principal Researcher**



**University of  
Leicester**

**School of Psychology - Clinical  
Section**

**DClinPsy Course**

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Date:

To: (Name and contact address of potential participants)

Dear (name of parents)

Re: Participation in a research study:

**Parental Coping with Paediatric Encephalitic Brain Injury**

I am currently planning a research study at Leicester University, as part of my professional training to be a clinical psychologist. The research is supported by the Encephalitis Society.

The study has been designed to explore how parents cope with their child's encephalitic brain injury. It also will examine whether differences exist in the way mothers and fathers attempt to cope with the impact of the illness.

I am interested in listening to couples, both mothers and fathers, from the Leicestershire, Derbyshire and Nottinghamshire area about their experiences of coping with a child with encephalitic brain injury.

The results of the study will be used by the Encephalitis Society and the healthcare community to increase awareness and understanding of childhood encephalitis and its impact on the lives of parents.

Enclosed with this letter is an information sheet describing the current study. I hope you can take time to read it and consider volunteering a couple of hours of your time.

If you are interested in taking part or would like further information, please complete the reply slip attached and return it in the pre-paid envelope provided. Alternatively, you can contact Elaine Dowell at the Encephalitis Society for further information on **01653 604366** or leave a message for me with Pamela Sawyer (course secretary) at the University of Leicester on **0116 223 1648**. In either case, I shall be happy to contact you and answer any questions you have or arrange a convenient time for us to meet.

I would like to thank you for taking the time to read this letter and hope to hear from you soon.

Yours sincerely,

Stephen Bainbridge  
Trainee Clinical Psychologist  
School of Psychology – Clinical Section  
109 Regent Road  
Leicester  
LE1 7LT

Please return the slip below in the enclosed pre-paid envelope

Thank you

.....

- I am interested in taking part in the above study and agree to Stephen Bainbridge contacting me.
- I understand that I am under no obligation to take part in the study

Name.....

Telephone No:.....

Date.....

### **Appendix 3. Participant Information Sheet**

**Participant Information Sheet**

**Title of Study:** **Parental coping with paediatric encephalitic brain injury**

**Principal Investigator:** Stephen Bainbridge  
Leicester University  
School of Psychology – Clinical Section  
104 Regent Road  
Leicester  
LE1 7LT  
Tel: 0116 223 1648

**Supervising Clinicians:** Dr. Keith Turner (Consultant Clinical Psychologist)  
Professor Mike Oddy (Brain Injury Rehabilitation Trust)

You and your partner are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Thank you for reading this.

**Who is conducting the study?**

I am Stephen Bainbridge, a trainee clinical psychologist at Leicester University. This study will be submitted as part of my Doctorate in Clinical Psychology.

**What is the purpose of the study?**

There is a significant body of research and published literature on childhood acquired brain injury. However, there is only a small literature on childhood encephalitic brain injury and even less on its impact on families. As a result, what is missing amongst healthcare professionals is an understanding of the effects of encephalitic brain injury on those who care for the injured child. This research attempts to partly fill this gap in knowledge.

The study will look at the way parents cope with their child's encephalitic brain injury from their *own* perspective.

Hopefully, the results of the study will help services to have a greater understanding of encephalitis and recognise the potential difficulties that parents experience in attempting to cope. The study will bring fathers' experiences into the picture and underscore the importance of offering services which emphasise and consider their needs, in addition to the needs of the mother.

### **Why have I been chosen?**

I am carrying out this study with the support of the Encephalitis Society, who will have written to you on our behalf. As you are a voluntary member of the society, you may remember in the past having completed a questionnaire listing a range of post-encephalitic difficulties your child may be experiencing. In order to conduct this research, we need the help of parents like you, who are in an excellent position to comment on the experiences of coping with the effects of childhood encephalitis.

### **Do I have to take part?**

It is up to you whether or not you decide to take part.

If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive or your voluntary membership to the Encephalitis Society.

### **What will happen if I agree to take part?**

- 1) You will be interviewed by me, as will your partner, but separately to one another; these will be informal interviews, very much like a conversation. It is essential to have two separate interviews like this as it allows your unique experiences to be heard and listened to properly.
- 2) I will ask you to talk about your experiences of coping with your child's encephalitis and how you manage and make sense of your experiences since your child was diagnosed with the illness. Each interview will last no more than 60 minutes and will be tape-recorded. You can stop for breaks during the interview at any time and if you don't feel able to finish the interview(s) in one day, another session can be arranged.
- 3) The interviews will then be written up. I will look at what you have said in detail along with other interviews to help identify the things that are most important to you in coping with your child's illness.
- 4) I may want to meet with you once more after all the interviews have been looked at in detail, in order to tell you some of my ideas and check whether I have understood you properly.

### **Will the information from the study be treated as confidential?**

Yes. During the interviews, only first names will be used and these will be changed when interviews are written up to make sure no one can identify you. The tapes will be identified using a number rather than your name.

When the interviews are written up, they will be stored on computer hard drive and will be protected by a password. Any computer disks will be locked away all the time when not being used. When the research has been completed, all identifiable information collected from you will be destroyed.

### **What are the possible disadvantages and risks of taking part?**

There are two possible disadvantages to being involved in this study. One problem may be that some of your time is taken up with participating in the interviews, approximately 60 minutes for each interview - around two hours in total.

This study aims to get your views and opinions; it is not designed in any way to interfere with your physical or psychological well-being. However, there is a small risk of you becoming emotionally upset while being interviewed. If you felt, through talking about your experiences, significantly distressed, you may need to take a break, stop the interview immediately and/or withdraw from the research altogether. Although unlikely, if you continue to feel emotionally unsettled following the interview and wish to speak to someone about resolving this, you can contact me at Leicester University on Tel: 0116 223 1648 or Elaine Dowell at the Encephalitis Society on Tel: 01653 604366.

### **What are the possible benefits of taking part?**

The opportunity to participate in this study provides you with a chance to share your experiences with a healthcare professional, maybe for the first time, of coping with a child with encephalitis. The information gathered in this study may also be used by the Encephalitis Society and other professionals to help improve and devise new services for supporting parents and families.

### **What will happen if I decide to not take part in the study?**

I will not contact you or your partner again and your voluntary membership to the Encephalitis Society will not be affected in any way.

### **Can I change my mind about taking part?**

Yes. You can change your mind at any time and you do not have to give a reason for doing so. Any information that I have already collected from you will be destroyed immediately.

### **What if I am harmed by the study?**

This research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

### **How can I find out what has happened to the research?**

When it is completed, a summary of the findings will be made available to you, should you wish to read it. The findings will also be printed in the Encephalitis Society Newsletter.

### **Who is organising and funding the research?**

This research is a necessary requirement for the successful completion of my Doctorate in Clinical Psychology course at the University of Leicester, funded by the workforce confederation. It is also being partly organised and supported by the Encephalitis Society.

### **Who has reviewed the study?**

Scientific review of this study has been undertaken by an independent member of academic staff from the School of Applied Psychology – Clinical Section. This research has been approved by the Leicestershire Research and Ethics Committee and the Encephalitis Support Group research ethics procedure.

### **What if I have more questions?**

You can contact me to discuss any questions you may still have at Leicester University on Tel: 0116 223 1648 or Elaine Dowell (National co-ordinator, Encephalitis Society) on Tel: 01653 604366, who will also be happy to help. Please feel free to discuss participation in this study with anyone you feel is relevant.

**Thank you for taking time to read this study information sheet .**

6<sup>th</sup> May 2004



#### **Appendix 4. Letter of ethical approval from LREC**

# Derbyshire Local Research Ethics Committees

3rd Floor  
Laurie House  
Colyear Street  
Derby  
DE1 1LJ

Telephone: 01332 868765 (direct line)

Fax: 01332 868785

email: [jenny.hancock@centralderby-pct.nhs.uk](mailto:jenny.hancock@centralderby-pct.nhs.uk)

22 September 2004

Mr Stephen Bainbridge  
University of Leicester  
Dept of Clinical Psychology  
104 Regent Road  
Leicester  
LE1 7LT

Dear Mr Bainbridge,

**Full title of study: Parental coping with paediatric encephalitic brain injury**

**REC reference number: 04/Q2401/68**

**Protocol number: 1**

Thank you for your letter of 28 August and emailed response of 21 September, responding to the Committee's request for further information on the above research.

The further information was considered at the meeting of Sub-Committee of the Derbyshire REC held on 21 September. A list of the members who were present at the meeting is attached.

## Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

## Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Application form		Dated: 12/07/2004	Date Received: 29/07/2004
Investigator CV		Dated: 12/07/2004	Date Received: 29/07/2004
Supervisor's CV		Dated: 12/07/2004	Date Received: 29/07/2004
Protocol	Version: 1	Dated: 12/07/2004	Date Received: 29/07/2004
Covering Letter		Dated: 28/08/2004	Date Received: 13/09/2004
Letter from Sponsor		Dated: 23/07/2004	Date Received: 29/07/2004
Interview Schedules/Topic Guides	Version: 1	Dated: 12/07/2004	Date Received: 29/07/2004
Letters of Invitation to Participants	Version: 3	Dated: 21/09/2004	Date Received: 21/09/2004
Participant Information Sheet	Version: 2	Dated: 29/08/2004	Date Received: 06/09/2004
Participant Consent Form	Version: 2	Dated: 29/08/2004	Date Received: 06/09/2004

Continued/

22 September 2004  
Mr Stephen Bainbridge

**Management approval**

You should arrange for all relevant host organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

**Notification of other bodies**

We shall notify Dr Keith Turner at the University of Leicester and Dr Dave Clarke at Leicester Partnership NHS Trust that the study has a favourable ethical opinion.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>REC reference number: 04/Q2401/68 Please quote this number on all correspondence</b>
---

Yours sincerely,

Jenny Hancock, Co-ordinator  
On behalf of  
Peter Korczak, Chairman  
Derbyshire Local Research Ethics Committee

*Enclosures    List of names and professions of members who were present at the meeting and those who submitted written comments*

*Standard approval conditions [ SL-AC2]*

**Appendix 5. Letter of ethical approval from the Encephalitis Society**



# The Encephalitis Society

action for support, awareness, and research

- the first ten years are  
just the start...



15 October 2004

Mr Stephen Bainbridge  
University of Leicester

Dear Stephen

Thank you for the copy of approval from Derbyshire Local Research Ethics Committees. The Encephalitis Society Research committee have now given approval for the project to commence.

We look forward to working with you.

Yours Sincerely

EL Down

Direct Dial: [redacted]

## **Appendix 6. Interview Schedule**

### **Introduction)**

- Current family composition
- Who is involved in the care of the child e.g. grandparents, child minders etc?
- How much time is spent caring for the child and by whom?
- Who works within the household (i.e. who works outside the home)

### **Life before encephalitis**

- Can you describe your son/daughter to me before their illness?
  - What are your thoughts and feelings about family life prior to their diagnosis of encephalitis?
- How is your daily life different now to before your son/daughters diagnosis?

### **Ways of coping**

- What types of difficulties arising from your son/daughter's encephalitis do you have to cope with? (**present**)
- What does coping mean to you? How do you personally define coping?
- External influences/pressures on child/family e.g. schooling (provision of education), bullying, friendships etc. Relationships with local authorities – sources of strain or assistance?
- How do you perceive or think about these difficulties? What influences how you view these?
- Themes of stress. How do these difficulties make you feel?
- **Style of coping (e.g. positive appraisal, attributions etc) Do you have a philosophy of life?**
- Ways of attempting to cope – strategies and variety in coping repertoire
- What works best in terms of coping? How do you judge **whether you're successful at coping?**
- Relationship between wider family, social support and coping
- Personal reflections of impact on self/relationship in relation to managing coping with stress

### **Coping and gender**

- Could you tell me some of the differences that exist between you and your partner in the way you both manage/cope with stress?
- How do you and your partner share coping responsibilities? Are there tasks that you do separately? Could you describe these to me?
- Are you or your partner better at using certain coping strategies than others? If so, can you tell me a bit more about this?
- Perceptions of the impact of child's injury on marriage/relationship/ relationship with siblings, wider family etc.

### **Severity of encephalitis**

Ordinary School or special School?  
Statemented (SATS Results)  
Additional support in school?  
Severity – Glasgow Coma Scale?

### **Experience of initial impact**

Initial reactions, thoughts, feelings  
Attempts at making sense of diagnosis  
What were the demands placed on you?  
What support did you receive – in what way was it helpful/unhelpful?

## **Appendix 7. Participant consent form**



# Leicestershire Partnership



NHS Trust

## PARTICIPANT CONSENT FORM

**Title of Study:** Parental coping with paediatric encephalitic brain injury.

**Principal Investigator:** Stephen Bainbridge

- I have read the Client Information Sheet and the nature of the research has been explained to me by Stephen Bainbridge. I have had the opportunity to discuss taking part in this research with Stephen, Elaine Dowell (National Co-ordinator, Encephalitis Society) and anyone else I considered important and I agree to take part in the above study.
- I understand that the interview with Stephen will be tape recorded and written out and that all the information about me or my views/experiences will remain confidential.
- I understand that I may withdraw from the study at any time without saying why and without this affecting my relationship with the Encephalitis Society.
- I understand what will happen to my responses after the interview and that the research will be written up and may be published in the future but that no one will be able to identify me.
- I understand that sections of any of my research records may be looked at by responsible individuals from regulatory authorities or from the Ethics Committee where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
- I understand medical research is covered for mishaps in the same as for patients undergoing treatment in the NHS i.e., compensation is only available if negligence occurs.

Signature of participant..... Date.....

Name in BLOCK CAPITALS.....

I confirm that I have explained the nature of the study as detailed in the Participant Information Sheet, in terms, which in my judgment are suited to the understanding of the client.

Signature of Investigator..... Date.....

## **Appendix 8. Coding extract**

Line Coding		Focused Coding
<p>1411 Making sense of diffic</p> <p>1413 Approaching puberty predicted as difficult time</p> <p>1414 Finding way through foggy area</p> <p>1415 used profess/people</p> <p>1416 Needing speech therapy?.</p> <p>1417 no help from local services</p> <p>1418 Buying services privately</p> <p>1419 making decision in future at predicted point</p> <p>1420 returning to mum role rather than case manager</p>	<p>/To understand and comprehend the difficulties [child's name] has [um] and to try and help her through it, to and also erm cos obviously we've got puberty coming up which we know is gonna be a difficult time and try you know I just think it helps you find your way through what can be quite a foggy area sometimes and you know if needs be you know it's people that have used you know I I just think now at some point if I need a speech that if I want to take on pri- you know get more speech therapy for [child's name] it's not gonna come through through local services so there's these these people would know of people that probably operate privately so that I could buy it in [um] if I decide at some point that I don't want to do this any more cos there's gonna come a point where I just want to get back to being a mum rather than a case manager cum whatever</p>	<p><b>Understanding diff. helps to support child through adolescence</b></p> <p><b>Using knowledge/past contacts helps to navigate through foggy times</b></p> <p><b>Seeking alternative solution as unable to get local services</b></p> <p><b>Role conflict?/returning to being mum at any cost</b></p>