A Qualitative Analysis of the Impact of Parental Acquired Brain Injury on Parenting and Parent Child Relationships

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Abstract

While previous research has demonstrated that acquired brain injury (ABI) exerts a substantial impact on the wider family system, little is known about the impact of parental brain injury on families with dependant children. The present study, therefore, examined the impact of parental ABI on parenting and parent-child relationships in two parent families. As ABI is assumed to impact upon the entire family system, the impact on the parenting of both the injured and non-injured parent was investigated. Semi-structured interviews were conducted with 10 non-injured parents whose partners had sustained an ABI in the last six years. The resultant data were analysed according to grounded theory procedures. A core category labelled ‘becoming the superordinate parent’ emerged. This encapsulated non-injured parents’ experiences of a shift in they and their partner’s parenting roles, relationships and expectations. Injured parents were described as struggling to meet the demands of their former parental role and non-injured parents appeared to adopt the roles and expectations no longer filled by their partner. Analysis also revealed that for many participants the transition to the role superordinate parent was not permanent, as their partners recovered at least some aspects of their previous parental role over time. The findings indicate, nevertheless, that acquired brain injury exerts a substantial impact on the parenting of both injured and non-injured parents, and professionals should consider the needs of the wider family when developing services for this population.
Introduction

Review of Previous Literature

Acquired Brain Injury

Acquired brain injury may result from a variety of causes. The term traumatic brain injury (TBI) is used to describe injuries which are caused by blunt impact, resulting from incidents such as falls, vehicular accidents and assaults. The broader term acquired brain injury (ABI) also encompasses damage secondary to other causes such as haemorrhage, tumour excision, hypoxia, infections and cerebral vascular accidents (strokes). All brain injuries are not equivalent, as the mechanisms of damage, their sequelae and recovery process differ between individuals for a variety of reasons including the type and severity of injury and pre-morbid characteristics. Some commonalities do exist, however, in the short and long term problems experienced by survivors of different types of brain injury (Hellawell & Pentland, 2001).

Motor and sensory deficits, fatigue, communication disorders and cognitive problems such as memory and concentration difficulties are amongst the commonly reported sequelae of ABI (Richardson, 1990). Although in the past researchers and clinicians have tended to concentrate their attentions on physical and cognitive problems; behavioural, social, personality and emotional changes are also common in individuals following brain injury (Kay & Cavallo, 1990). These symptoms include withdrawal, social problems, lack of initiative, inappropriateness, aggression, agitation, lack of insight, emotional lability, and irritability. (Caine & Watson, 2000; Hellawell & Pentland, 2001; Milders et al, 2003; Deb et al, 1999). Affective symptoms such as anxiety and depression are also commonly observed sequelae in individuals who have sustained a brain injury (Douglas & Spellacy, 1996; Linn et al, 1994; Morris et al, 2002). Such emotional and social problems are thought to be amongst the most debilitating sequelae for brain injury survivors and have been linked with poorer social adjustment, inability to return to work and loss of social contact (Kersel et al, 2000).
Impact on Family Members and Family Relationships

Such symptoms are clearly distressing and exert a substantial and prolonged impact on the lives of brain injury survivors. Since the 1970’s awareness has grown that ABI and its sequelae exert an influence not only on the survivor, but also on the survivor’s family (Florian & Katz, 1991; Perlesz et al, 1999). The effect on the family of a relative’s TBI has obtained substantial attention from researchers. The impact of other forms of ABI on the families of survivors has received less attention, although the effects of stroke on the family system have been studied to a lesser extent (Han & Haley, 1999). As the present study includes individuals who have sustained both traumatic and non-traumatic injuries in its sample, this introduction will draw on the available literature related to both traumatic and non-traumatic injuries to place the study within the appropriate context.

This research has consistently shown that ABI places substantial strain on family relationships and that these relationships may become disrupted whilst the injured individual and their family attempt to adjust to the injury and its ongoing social, behavioural and emotional sequelae (Maitz, 1990). Researchers have found evidence that the family relationships of individuals with TBI may be marked with conflict and friction during the first two years post injury (Oddy et al, 1978). Marital relationships amongst traumatically injured patients have been found to be less well adjusted, less openly affectionate, and marked with increased disagreement, difficulty in reaching joint decisions (Moore et al, 1991) and conflict (Wood et al, 2005).

Rates of marital separation and divorce are also substantially higher in this population. Wood and Yurdakul (1997) found that amongst a group TBI patients with varying severities of injury, 49% of marital and cohabiting relationships broke down, resulting in separation or divorce in the first 5 to 8 years post injury. Such figures evidence the substantial strain a brain injury, its accompanying symptoms and the necessary changes in family roles, may place on close relationships.
Such changes within the family have been found to cause substantial distress in the family members of injured individuals. Primary caregivers (mainly spouses and mothers) of severely traumatically brain injured individuals have, for example, been reported to experience medium to high levels of 'subjective burden' or strain for up to seven years post injury (Brooks et al, 1987). Elevated levels of psychological difficulties, such as anxiety and depression have also been frequently noted in the relatives of individuals with both TBI (Linn et al, 1994; Livingston, et al, 1985 Marsh et al, 1998) and stroke (Grant et al, 2004; Dennis et al, 1998; Han & Haley, 1999).

The distress experienced by family members has been hypothesised to arise from various factors including relationship change, family role changes, levels of social support, personal coping strategies and the caring burden assumed by family members (Leathem et al, 1998; Lezak, 1988; Marsh et al, 1998; Sanders et al, 1997). Although predictors of psychological distress are less well established in other causes of ABI such as stroke (Han & Haley, 1999) a consistent finding amongst TBI populations is that negative behavioural and personality changes are more predictive of relatives’ distress than physical disabilities, cognitive problems or initial injury severity and exert a disproportionate effect on family members’ well-being (Ergh et al, 2002; Groom et al, 1988; Marsh et al, 1998; Kreutzer et al, 1994b, Ponsford et al, 2003).

Impact on Non-Main Caregiver and Dependant Children

With some exceptions, this accumulating body of work has largely restricted itself to examining the impact on individual adult family members, most commonly the primary caregivers of the injured family member. Although less is known about the impact on other family members and their relationships with the injured individual, there is some evidence to suggest that a family member’s brain injury exerts a wider influence. Perlesz et al (2000), for example, found that secondary and tertiary carers of TBI patients also reported symptoms of distress, particularly anger and fatigue.
Despite an acknowledged need for further investigation in this area (Perlesz et al, 1999; Visser-Meiley et al, 2005a), little research has examined the impact of parental brain injury on the well being of their children. To date it appears that only four empirical studies exist in this area, two focussing on TBI (Pessar et al, 1993; Uysal et al 1998) and two related studies on children of stroke survivors (Visser-Meiley et al, 2005ab). Some conflicting results have been obtained from these studies, with one study reporting a heightened risk of behavioural problems in children of parents who have sustained a TBI (Pessar et al, 1992) and one study with superior measures and methodology but a smaller sample size of 18 children finding no such association (Uysal et al, 1998). The latter study did, however, report that children in their sample were significantly more likely to self-report symptoms of depression on the Children’s Depression Inventory (Kovacs, 1985) compared to control children.

With regards to stroke, Visser-Meiley et al (2005ab) reported that amongst a sample of 54 children aged between four and eighteen, 54% showed an elevated score on either the Child Behaviour Checklist (Achenbach, & Edelbrock, 1983) or Children’s Depression Inventory, with 21% of children scoring in the clinical range on at least one measure. Of these studies only Uysal et al (1998) utilised a control group and all three studies had small sample sizes and heterogeneous age groups. As such, to date, although there is some evidence to suggest that they may present a more at risk group, the type or extent of the impact of parental brain injury on the psychological adjustment of children remains relatively ambiguous.

**Family Functioning and Brain Injury**

As the above studies demonstrate, there has been a shift in the last decade where researchers have begun to look beyond the principal caregiver and look at all family members or the entire family system as the unit of analysis (Kay & Cavallo, 1990; Palmer & Glass, 2003). This shift in focus has been influenced by family systems theory. This theory, derived from general systems theory, is built on several central tenets: that all individuals within the family system are connected with one another, that these connections evolve
over time and that a significant change in one aspect of the system will result in changes for all members (Minuchin, 1974). Consequently, from a family systems perspective we would expect brain injury and its sequelae to impact on the whole family system, how it organises itself, the roles assumed by different members and how these members relate to one another (Gan & Schuller, 2002; Leaf,1993). Maitz (1990), for example, argues that a family member’s brain injury may force a redistribution of their roles to other family members. If this transition is sudden or unwanted by either the injured or non-injured family member, it may stress the family system leading to disequilibrium and family dysfunction.

Evidence of the profound impact of ABI on the wider family system has been gathered by researchers investigating the impact of ABI on family functioning (i.e. how family members interact and work together). Researchers have frequently utilised the McMaster Family Assessment (Epstein, et al, 1983) to investigate family functioning the families of brain injury survivors. Using this measure researchers have repeatedly found evidence of heightened levels of family dysfunction amongst families affected by TBI compared to normed samples (Groom et al, 1998; Ergh et al, 2002; Gan & Schuller, 2002).

Specific family functioning difficulties noted by researchers include communication difficulties, affective involvement, and family roles (Ergh, 2002; Kreutzer et al, 1994a). In stroke populations, whilst some authors have not found a deleterious effect on family functioning (Bishop et al, 1986) others have found increases in levels of family conflict (Clark et al, 2004) and disturbances to roles, family communication and general functioning (Clark & Smith, 1999).

Similar predictor variables have been shown to be associated with family functioning in TBI samples to those involved in caregiver distress. Neurobehavioural symptoms such as inappropriateness and affective symptoms such as depression have been frequently noted to be amongst the strongest predictors of family functioning (Douglas & Spellacy, 1996; Groom et al, 1994; Ergh et al, 2002; Kreutzer et al 1994b;
Some researchers have suggested that family functioning may improve over time and that families have the potential to adjust and resume healthier modes of functioning in some areas. In a cross sectional sample, Kreutzer et al (1994b), for example, found that increasing months post injury predicted more affective involvement and greater affective responsiveness in TBI family members. Other researchers have, however, found that family functioning does not improve (Gan & Schuller, 2002; Groom et al, 1994) or may worsen (Ergh et al, 2002) over time and therefore conclude that, like caregiver stress (Brooks et al, 1987), the impact of ABI on family member does not dissipate over time. Kay and Cavallo (1990) propose that these disparate findings may arise as some families are able to evolve and, after an initial period of crisis, adapt the family system to accommodate both the needs of the injured individual and other family members. They also speculate, however, that other families will not be able to accomplish this process of adaptation and their functioning will continue to be stressed (Kay & Cavallo, 1990).

Consequently, research to date suggests that the families and family relationships of adult brain injury survivors may be marked with conflict, low levels of affective involvement, impaired communication and dysfunctional roles. Furthermore, at least amongst TBI samples, family dysfunction is likely to be more prevalent amongst families where the injured individual exhibits negative personality or behavioural changes regardless of the severity of the initial injury.

Although this research has clearly demonstrated that ABI in a family member may profoundly affect the family system, some methodological weaknesses should be noted when interpreting the above findings. Firstly, much of the research has been conducted without the use of control groups and hence it is difficult
to delineate what difficulties may be attributable to the effects of ABI and which may be attributable to general disability or the pre-injury characteristics of the family (Douglas and Spellacy, 1996). This criticism is particularly important in studies which have utilised a TBI population, as individuals who sustain TBI are more likely to engage in high risk or antisocial behaviours pre-morbidly (Kreutzer et al, 1994a). It is likely, therefore, that these patients and their families may be characterised by pre-injury psychological, psychosocial and family problems (Kreutzer et al, 1994a). Thus adverse family functioning may be best viewed as a combination of pre-morbid family characteristics and the stress produced by caring for an injured family member (Kreutzer et al, 1994a).

Secondly, as family and marital break up are common in families following brain injury (Wood & Yurdakul, 1999), the fact that the above studies only included families which remained intact at the time of assessment, may indicate that they represented a better adjusted sub-sample of families and this again makes these results difficult to interpret.

In addition, no study to date has specifically looked at family functioning within families with children where a parent has sustained a brain injury. The results of the existing studies are likely to be relevant, however, as researchers have found that neither family composition type (i.e. families with or without children) or the relationship of the respondent to the injured individual (i.e. parent, spouse, sibling or child) result in a significant difference in the estimate of family functioning obtained (Douglas and Spellacy, 1996; Gan & Schuller, 2002).

Parent-Child Relationships and Parenting following Acquired Brain Injury

Although many injured individuals may have dependant children at the time of injury (Urbach, 1989; Uysal et al, 1998), very little research to date has specifically examined how parental brain injury impacts on family functioning, parenting behaviour or child-parent relationships within such families. In the wider
field of chronic illness and disability research, however, it has long been argued that existence of parental chronic illness or disability may influence parenting practices, roles and relationships (Kelly & Anjoo, 1997). Although most previous research done in this wider area has focussed on the impact of parental illness on child development, rather than its impact on parenting and parent child relationships, there is some evidence to suggest that parental chronic illness may exert a detrimental impact on parenting abilities, including difficulties with decreased energy and increased reliance on the healthy spouse (Lundwall, 2002; Rehm & Cantzaro, 1888; Smith & Soliday, 2001). Consequently, given the potentially profound effect of parental ABI on an individual’s social, emotional and cognitive functioning it seems reasonable that these sequelae may affect the individual’s functioning as a parent.

Although the majority of research on families with a brain injured member has focused on the impact on adult family members and their relationships with the brain injured individual, a handful of studies have specifically looked at the impact on parenting and parent-child relationships. Again almost all of this research has focused on TBI populations, with a recent qualitative study by Butera-Prinzi & Perlesz (2004) constituting a notable exception. Although a few authors have considered the impact of stroke on parenting, these tend to focus on physical aspects of child care and there is a paucity of literature on the impact of cognitive, emotional and social changes in this population (Culler, Jasch & Scanlon, 1994)

**Clinical Observations**

Several authors have discussed the potential impact of TBI on the survivor’s relationship with their children (Lezak, 1978; 1988; Urbach, 1989; Urbach & Culbert, 1991; Urbach et al, 1994). As with other literature on parental health problems and parenting (Kelley & Anjoo, 1997), much of this literature has been informed by clinical experience rather than research evidence. These observations generally describe parental ABI as having a fairly catastrophic impact on parenting and parent-child relationships. Such difficulties are proposed to stem from both the emotional and social difficulties and the cognitive sequelae resulting from the injury.
Lezak (1978; 1988), for example, states that the brain injured parent may bully or belittle their children due to a combination of poor impulse control, frustration and a need to regain a sense of mastery in their lives. Urbach et al (1994) go as far as to speculate that relations between the brain injured parent and their child may become marked by a sense of jealousy and rivalry, related to both the child’s developing competencies and competition for the non-injured parent’s attention. Alternatively, these authors propose that the relationship may one of distance and emotional detachment as the depressed or socially withdrawn brain injured parent is presumed to decrease their engagement with their child.

In either case, these changes are proposed to result in a breakdown in parent child relationships and associated feelings of stress, shame, guilt and anger in the child (Lezak, 1978; Urbach, 1989; Urbach & Culbert, 1991; Urbach et al, 1994). The same authors have also argued that this relationship breakdown and ongoing stress for the child will increase the risk of childhood emotional or psychological difficulties (Lezak, 1978; Urbach, 1989; Urbach & Culbert, 1991; Urbach et al, 1994). Lezak also speculates that relationships may deteriorate to such an extent that older, more independent children are likely to attempt to avoid the disabled parent, perhaps even to the extent of leaving home (Lezak, 1978; 1988).

Besides these social difficulties, it has also been argued that difficulties in cognitive functions such as attention, memory, organising and planning will impair the brain injured person’s ability to perform adequately as a parent. Ducharme and colleagues (Ducharme et al, 2002; Ducharme, 2003) suggest that brain injured parents are likely to miss cues to reward positive child behaviour with warmth and praise and may also overreact to mild child misbehaviours. This may compromise parent child relationships and contribute to a deterioration in child behaviour. Ducharme and colleagues state that such a deterioration may result in an increase in coercive and punitive tactics aimed at regaining control of child behaviour and that such a cycle, especially if combined with difficulties in impulse control, increases the potential for physical or emotional abuse.
Cleary the above predictions are dire indeed, but some caution should be exercised regarding the above hypotheses. None of the above hypotheses are drawn from research evidence but are instead drawn from observations amongst treatment seeking populations. Sensational as these accounts are, they are principally aimed at alerting clinicians to the possible risks in families affected by ABI, rather than representing a balanced account of all families. It is therefore, possible that these represent an extreme end of a continuum of possible family reactions to parental ABI.

Quantitative Studies

The influence of parental brain injury on parent child relationships and parenting skills has also been investigated by researchers using quantitative methods on relatively small sample sizes. Pessar et al (1993) conducted the first published research study of the impact of parental brain injury on parenting and child behaviour. They utilised a sample of 24 two-parent families encompassing a total of 56 children between the ages of 2 and 23, interviewing the non-injured parent in these families. All injuries were traumatic in nature had occurred on average 46 months prior to the study.

Using a specially constructed questionnaire, Pessar et al (1993) found that problems in the relationship with the injured parent were the most frequently reported child problem in this sample, being more commonly reported than externalizing or emotional problems. All the non-injured parents questioned described negative changes in the child’s relationship with the injured parent, such as not wanting to spend time with them or a decrease in affection toward them, with 10 parents reporting this to be a substantial problem, and 14 parents describing this as a less frequent problem.

Twenty-three of the twenty-four non-injured parents also reported changes in the injured parent’s behaviour with the children, of which an increase in negative behaviours such as arguing or yelling at
children was most frequent. The next most commonly reported problem was decreased frequency of positive behaviours such as praising or having fun with the children, followed by difficulties with fulfilment of the parental role such as helping with or being responsible for the children.

Pessar et al (1994) also found that the severity of child relationship problems correlated significantly with the children's age at the time of the study, with teenagers experiencing the greatest difficulties. In addition, reduced fulfilment of the parental role and reduced positive behaviour by the injured parent was also found to correlate significantly with child relationship difficulties. Consequently, these results appear to partially support the predictions made by earlier authors, as they demonstrate a deterioration in the child's relationship and behaviour towards their parent, which may be related to changes in the injured parent's parenting behaviour. Pessar et al (1994), however, utilised a non-validated questionnaire containing 11 items related to perceived changes in child behaviour, 3 of which were purported to target relationship problems, and 8 further items on perceived changes in the injured parent's behaviour toward the child. It, therefore be unwise to draw any strong conclusions regarding parent child relationships post brain injury on the basis of responses to three questions on an un-validated questionnaire, particularly in the absence of a control group.

Further drawbacks of this study relate to the sample utilised. Although all the children considered in the study resided with their parents, this study included a very wide age range, from 2 to 23 years of age. It is likely, therefore, that the developmental tasks faced by the children and the skills required in parenting are hugely different at different ends of Pessar et al’s age range. It may, therefore, be unwise to consider children at such different ages together and attempt to draw a general conclusion.

In addition, as noted by Linn et al (1994), Pessar's sample were recruited from a group of volunteers participating in a series of retreat weekends focusing on psychological and family issues related to brain
injury. Consequently families experiencing difficulties with family relationships may be over represented in their sample.

Uysal et al (1998) carried out one of the only investigations to date focusing specifically on the influence of brain injury on parenting behaviours. These authors compared a sample of 16 families where a parent had sustained TBI with children aged between seven and eighteen years (mean age 14) with a sample of families without disabilities on several measures of parenting and child adjustment. Using a 117-item questionnaire which attempted to assess different parental behaviours such as acceptance, involvement and control, Uysal and colleagues found that parents who had suffered TBI described themselves as setting less goals and boundaries for their children, being less encouraging of skill development, being less nurturing and less actively involved with their children. Parents with TBI did not differ from control parents, however, in terms of strictness, rejection, and acceptance. Neither did they differ with regard to the frequency of favourable or unfavourable parental practices as measured by the Parental Practices Questionnaire (Strayhorn & Wideman, 1998). Uysal et al interpret these findings as indicating that parents with ABI may fare less well in parenting tasks which place more cognitive demands on the parent.

When the children’s own reports of parenting behaviour (measured on the same questionnaire) were examined, few differences were found between the index and control groups. The only significant difference that emerged was that children of brain-injured parents perceived both parents as exercising more lax control (e.g. not setting rules, ignoring misbehaviour). Uysal et al (1998) ascribe this difference between injured parents and their children’s perception of parenting to a possible ‘halo’ effect, wherein the children perceive their parents to be doing well in spite of their disabilities. The authors, however, also considered a second explanation for the disparity between child and parent self-report. As might be expected, injured parents endorsed more symptoms on the Beck Depression Inventory (Beck et al, 1961) than control parents and it is possible that depressogenic thinking and self-criticism coloured the injured parents’ perceptions of their own parenting abilities. Thus from Uysal’s results it is difficult to conclude
with any certainty whether their results represent a true difference in parenting behaviour between injured and non-injured samples. In addition, the use of a small sample size of 16 families makes their results all the more difficult to draw definite conclusions from.

Uysal et al (1998) also questioned whether selection bias could have influenced the results of their study as individuals who had separated and were no longer living with their children were excluded. This may indicate that their sample reflects a better adjusted section of individuals who are able to cope and maintain relationships post TBI. Indeed, the fact that the sample of 18 injured families included 8 families where the injured individual parented as a single parent may indicate that this particular sample included an over representative number of parents who were functioning very well. In addition to the overall small sample size, the study’s results may be weakened by the fact that the sample was very heterogeneous in terms of injury severity and time since injury. Some participants, for example, had sustained injury during their own childhood and participants were between 2 and 39 years post injury at the time of the study.

Qualitative Studies

To date one qualitative study of parent child relationships post ABI has been published by Butera-Prinzi & Perlesz (2004). These authors conducted in-depth interviews and observations over a 6 month period with 4 children aged 9 to 12 whose fathers had experienced ABI (resulting from haemorrhage or tumour removal). The main themes uncovered in interviews reflected the children’s difficulties adjusting to the changes in their fathers. The children reported feeling embarrassed by the changes in their fathers and described experiencing a grief reaction to the loss of their ‘real father’ which they felt they could not express openly due to family loyalties.

This echoes previous hypotheses by Urbach and colleagues (Urbach, 1989; Urbach & Culbert, 1991) who suggested that parent-child-relationships with a brain injured parent will be marked by a profound sense of
loss and that children faced with a characterologically changed parent face a more difficult adjustment than those children whose parent dies as a result of ABI (Urbach 1989, Urbach & Culbert, 1991). They argue that these children are faced with the 'loss' of their original parent but are unable to mourn for this parent in the usual way (Urbach et al, 1994).

The children interviewed by Butera-Prinzi and Perlesz also described experiencing conflicting emotions toward their injured parent, as although they continued to maintain an emotional bond with their father, they also experienced feelings of anger and hostility when faced with their father's altered behaviour, changed personality and emotional disengagement. The authors state that the children dealt with this conflict in part by decreasing their interaction with their fathers.

Strikingly, Butera-Prinzi and Perlesz state that all 3 families in their sample reported experiencing significant levels of verbal and physical violence, such as punching, choking and smacking. Similar concerns regarding violence in parent-child relationships have been voiced by other authors (Ducharme 2003; Ducharme et al 2002; Lezak, 1978; 1988). The three families who participated in Butera-Prinzi and Perlesz's study were, however, drawn from families involved in a multiple family group intervention within a family therapy service and as such may represent a biased sample with particular family and relationship difficulties. Consequently, although these authors raise an important point for clinicians regarding assessment of child protection issues within brain injured families, it is unclear whether this problem is common amongst all such families, especially those not referred to child and family treatment services.

**Impact of ABI on the Relationships and Behaviour of the Non-Injured Parent**

It is unlikely that the above changes in the parenting of the injured spouse occur in isolation. If we view the family from a systems perspective it seems likely that the changes wrought by the brain injury will
have a wider effect and it appears reasonable to expect that, in two parent families, any changes in the parenting of the injured parent will impact upon the relationships and role of the non-injured parent (Maitz & Sachs, 1995).

Such questions have been considered by authors for some time. It has been argued that the increased burden placed on the non-injured spouse, related to caring for the injured individual and the performance of roles previously fulfilled by the injured parent, will consume the non-injured parent’s attention and resources and lead to a decrease in their ability to perform their parental role adequately (Uysal et al, 1998; Lezak, 1978; Visser-Meiley et al, 2005ab). Butera-Prinzi & Perlesz's (2005) study found some support for this hypothesis, as the four children in their study described experiencing a sense of having to compete for the non-injured parent’s attention, with a consequent decrease in levels of practical support.

Other empirical support has been found for the hypothesis that the parenting of the non-injured parent will be disrupted. Using the same measures described previously, Uysal et al (1998) found that non-injured spouses described themselves as having a less warm, loving and accepting parenting style when compared to control families. Uysal et al (1998) attribute this difference in parenting behaviour to the increased caring burden and extra responsibilities assumed to placed on these parents. As the authors did not include a measure of change in responsibility or burden; this relationship, however, remains speculative. Caution should also be exercised when interpreting these results as Uysal et al’s sample of non-injured parents comprised only 8 individuals, as 8 of the index families were single parent families (headed by the injured parent) and two spouses from intact families did not participate.

Pessar et al (1994) also investigated the impact of a parent’s brain injury on the parenting of their non-injured spouse by administering a four-item parental performance questionnaire to non-injured parents. Reduced parental performance in the non-injured parent was found to correlate with child emotional,
behavioural and relationship difficulties, and did so more strongly than any measure of parenting or behaviour change in the injured parent. Similarly Visser-Meiley et al (2005ab) found that child emotional problems were unrelated to injured parent characteristics but were correlated with a measure of caregiver strain in the non-injured parent.

These results, therefore, begin to suggest that a parental brain injury may also affect the parenting of the non-injured parent. They also raise the possibility that any influence on child well-being may be mediated via the non-injured parent’s behaviour and it possible that the non-injured parent serves as a buffer and may compensate for effects of the injured parent’s difficulties in some circumstances. Such findings, therefore, underline the importance of considering and investigating the parenting of both the injured and the non-injured parent in two parent families affected by ABI.

Summary of Previous Literature

The previous research in this area indicates that ABI exerts a profound impact on the family system and family relationships. Although there is an accumulating body of work on how ABI affects family members, the majority of this work has examined the impact on adult family members and their relationship with the injured individual. Evidence of increased depressive symptoms and behavioural difficulties in the children of injured individuals indicates that children are also affected by changes wrought by a family member’s brain injury. There has, however, been relatively little research specifically examining parent child relationships in families affected by ABI and little is known about how these may change after a parent’s brain injury. As family members’ reactions and changes in their relationships will depend on their pre-existing relationship (Kreutzer et al, 1992), this question appears to warrant individual exploration. In addition, although there is a great deal of speculation regarding how ABI impacts upon the injured parent’s parenting behaviour, little research has examined this area to date and it is unclear how ABI affects the functioning of individuals in accomplishing the often difficult and demanding tasks
parenting encompasses. Similarly, although it may seem reasonable to expect that parental ABI will also influence the parenting and role of the non-injured parent, this has also received little investigation.

Such a gap in the literature is significant as factors such as parenting behaviour and parent-child relationships are known to be important for child development and are argued to be key mechanisms in the link between parental illness and child outcome (Amistead et al, 1995). As noted above, although few studies have examined child adjustment in the families of adult ABI survivors, the scant literature to date suggests that these children may be at increased risk of behaviour or affective difficulties. Albeit the development of such problems is likely to result from a multitude of factors besides parental factors, these findings, combined with the acknowledged importance of parental factors for child development, underline the importance of a more thorough examination of the impact of parental brain injury on parenting and parent-child relationships.

The Current Study

Aims of the Current study

The present study aims, therefore, to tackle this gap in the literature and examine the impact that a parent sustaining an ABI has upon parent child relationships and parenting. The relationships and parenting of both the injured and non-injured parents will be examined, as any change in the parenting or relationship of one parent is likely to impact on the other. A secondary aim of the study is, therefore, to examine the processes whereby the parenting of one parent impacts on the parenting of the other, in order to obtain a full account of the impact of ABI on the parenting system.

A qualitative approach was chosen to address this research question. This approach was chosen for two main reasons. Firstly qualitative research methods offer the researcher an inductive approach where new theory and hypotheses can be generated, rather than testing existing theories (Glaser & Strauss, 1967).
Consequently qualitative methods are particularly useful in areas, such as the present one, where little previous research has been conducted. Secondly, a qualitative approach enables the exploration of participants’ experiences in depth and attempts to generate an understanding of the meaning of these experiences. As such, qualitative research can be a useful approach when considering complex interlinking phenomenon such as emotions, thought processes and relationship changes which are difficult to capture fully using standardised quantitative methods (Flick, 1998; Strauss & Corbin, 1998). A qualitative approach, therefore, provides an opportunity to investigate the complex area of parenting and relationships and offers the researcher the opportunity to begin the research from a broad, open focus rather than attempting to derive hypotheses from a relatively small pre-existing literature.

**Choice of Informant**

The present study will examine these changes from the viewpoint of the non-injured parent in two parent families and will seek to develop an understanding of this parents’ perspective of the changes in parenting within a family affected by ABI. Although it is acknowledged that the use of a single informant from each family restricts the scope of the research to one particular perspective, this approach was chosen for several reasons.

Firstly, it was felt that non-injured parents would be less likely to experience difficulties with memory or communication problems than their injured partners. There is also some evidence that injured family members report less changes in family functioning than non-injured relatives (Gan & Schuller, 2002). These authors, therefore, conclude that individuals with ABI may lack insight into changes in family functioning and have less awareness of the impact of ABI on the family than their partners (Gan & Schuller, 2002).
Although such a conclusion may be criticised for unquestioningly privileging the view of the non-injured relative as more ‘correct’ than that of the injured-parent, this study also demonstrates that injured and non-injured family members may have differing views of their family life. Consequently it was felt that the use of a single informant would render the study an appropriate and manageable size and allow the in-depth exploration of one perspective rather than a more superficial rendering of two differing perspectives.

**Grounded Theory**

A design based on grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) was selected. The term grounded theory refers to both a method of analysis and the product of this analysis. The method consists of a detailed and systematic set of procedures for collecting, categorising and conceptualising data (Strauss & Corbin, 1998). This methodology aims to generate an understanding of participant’s experiences and build an account of that experience in the form of a grounded theory (Strauss & Corbin, 1998). Strauss and Corbin define a grounded theory as a ‘set of well developed concepts related through statements of relationship, which together constitute an integrated framework which can be used to describe or predict phenomena.’ (Strauss & Corbin, 1998; pg 15). A grounded theory, therefore, represents a theoretical understanding or explanatory framework for the phenomenon under investigation (Charmaz, 2006).

This theoretical understanding of participants’ experiences is generated by examining data about the phenomenon under consideration (Strauss & Corbin, 1998). In this case the data examined will be individual interviews with non-injured parents conducted by the researcher. Coding in grounded theory proceeds in a stepwise fashion. In the initial stages coding focuses on identifying and labelling basic concepts in the data. Analysis proceeds via the method of constant comparison, as segments of data are continually compared with one another in order to delineate salient differences and similarities between concepts. This allows the organisation of concepts into higher level categories which represent
progressively more abstract concepts. These higher level categories aim to interpret rather than merely label the data under consideration.

In grounded theory research, data collection and analysis proceed concurrently and further data collection focuses on gathering more information regarding the emerging categories and their relationships. In this way the researcher may start with a relatively open question but will progressively refine their research focus as the analysis proceeds.

Grounded theory procedures, therefore, offer an inductive, bottom up approach to analysis and data collection, where the analysis is gradually built up to a more abstract and conceptual level with the full picture of the phenomenon only emerging from the data at the end of analysis. In this way the resultant theory is said to emerge from the data and fit closely with it, rather than being constructed from preconceived theories and ideas. Consequently, the theory that is generated is grounded in the data which has been collected from participants and should closely reflect their construction and perception of the world. In addition, as the interpretation of the data is delayed until the later stages of analysis, grounded theory procedures may also be less likely to force data into preconceived categories and such an approach may be particularly helpful when approaching a value laden topic such as parenting.

**Emergence, Construction and Reflexivity**

In their initial formulation of grounded theory, Glaser and Strauss (1967) appear to advocate a positivist approach to epistemology as they emphasise the discovery and emergence of theory, relatively uninfluenced by researcher. The stance, which indicates that ideas can ‘emerge’ independently from the data and that a grounded theory represents a pre-existing theory which is discovered by a neutral observer, has been challenged and revised over the years (Charmaz, 2005; 2006; Henwood & Pigeon, 1997). Such revisions are often referred to as constructivist grounded theory (Charmaz, 2005; 2006).
These reworkings acknowledge the role of the participant, researcher and the research process in constructing the version of reality captured by the resultant theory. This view acknowledges that both the researcher and the participant bring with them previous experiences, goals and assumptions that shape the nature of the data and the resultant theory. Amongst other factors, the participant’s account is shaped by the questions asked, the nature of their relationship with the interviewer and the context of the interview. Consequently, the account given by participants reflects a particular time, place and context, rather than the only possible perspective of their experiences (Charmaz, 2006; Potter & Hepburn, 2005).

These challenges to Glaser and Strauss’s original stance also argue that, as the researcher engages with the data and attempts to impose meaning and structure to it, the process of grounded theory necessarily contains an interpretive element. Consequently, the researcher is best seen as an active participant in the research process rather than a neutral observer, who uncovers pre-existing theories (Charmaz, 2006). Strauss and Corbin (1998), for example, acknowledge the interpretive nature of analysis stating that ‘analysis is interplay between researcher and the data.’ (Strauss & Corbin, 1998, pg 13).

Consequently all observations and interpretations are derived from a particular standpoint as the researcher approaches the subject with their own prior ideas, experience and professional assumptions. The resultant grounded theory, therefore, is best viewed as a construction; generated by the researcher and participants and their interaction with the data (Charmaz, 2006). The theory constitutes an interpretation or reading of the data which may be open to reinterpretation, rather than the only possible perspective on the phenomenon.

The acknowledgement of the researcher’s contribution to theory generation necessitates the adoption of a reflexive stance towards the data (Charmaz, 2006; Pigeon & Henwood, 1997). This stance involves
developing an awareness of one's prior assumptions, professional background and the context of the research and scrutinising how these may interact with the data and shape the researcher's understanding of it. By reflecting on this process and checking how their assumptions relate to the theory produced, the researcher can attempt to minimise the influence of preconceived ideas in their work (Charmaz, 2006).

It is also acknowledged, however, that the researcher can never entirely step outside of the subject matter or completely bracket their own assumptions (Willig, 2001). A second purpose of reflexivity, therefore, to generate an awareness of the factors which may have influenced analysis and disclose these to readers, in order that they may to evaluate how these may have influenced the data and consider possible alternative interpretations (Charmaz, 2006; Elliot, Fischer & Rennie, 1999).

Consequently the acknowledgement and consideration of the interpretive elements in theory and the adoption of a reflexive stance strengthen the resultant grounded theory and help the researcher and the reader to become aware of preconceptions and move toward a more 'truthful' position (Parker, 2005).

Summary of Aims of the Current Study

The present study, therefore, aims to use grounded theory techniques to investigate the current research question, whilst acknowledging the active role of the researcher in the research process and the importance of taking a reflexive stance towards the data. More specifically, the present study aims to examine the non-injured parent's experiences of the impact of parental ABI on parent-child relationships and parenting. A secondary aim of the study is to generate an understanding of how changes to the parenting of one parent may impact on the parenting of the other, in order to obtain a full account of the impact of ABI on the parenting system. These questions will be investigated by conducting individual interviews with the non-injured parent in families affected by parental ABI.
Method

Design

Data collection and analysis were conducted according to grounded theory procedures (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990). These consist of a detailed but flexible set of procedures for collecting, categorising and conceptualising the data (Strauss & Corbin, 1990).

Participants

Potential participants were identified from amongst past and current clients of Clinical Neuropsychology Services within two geographical areas.

Identification of Clients at Site One

A database of previous clients was consulted to identify all clients currently under the age of 60, seen within the last 6 years with one of the following conditions: closed head injury; open head injury; hydrocephalus; encephalitis; post-concussional syndrome; anoxia; tumour removal; subarachnoid haemorrhage; intracranial haemorrhage. Clinicians were then asked to identify those clients who did or did not have children. Where clinicians were uncertain, patient files were examined to establish if clients met inclusion and exclusion criteria.

Identification of Clients at Site Two

The extensive file search generated few clients with children beyond those identified by clinicians at site one, as family composition was rarely recorded in files. Clients at site two were, therefore, identified solely by clinicians within that department.
Inclusion criteria

- Families where one parent had sustained an acquired brain injury (closed head injury; open head injury; hydrocephalus; encephalitis; anoxia; tumour removal; subarachnoid haemorrhage; intracranial haemorrhage) in the last 6 years.
- Families with children aged between 0 and 16 at the time of injury.
- Families where both parents have resided together and co-parented for a period of at least 6 months post injury. As levels of marital break up are high within acquired brain injury samples (Wood & Yurdakul, 1997) both currently cohabiting and couples who had separated after six months of cohabitation were included.

Exclusion criteria

- Families where the brain injured parent sustained injury less than 6 months previously.
- Families where the non-injured parent had special communication needs or limited comprehension of English.
- Families where the injured parent was deemed incapable of consenting to participation by the Clinical Neuropsychologist who had previously worked with and assessed the patient.

Procedure

Pilot interviews

Initially four pilot interviews were held with volunteer colleagues from the Department of Child and Family Mental Health. During these interviews colleagues were asked to discuss significant experiences which impacted upon their own or their partner’s parenting. The purpose of these interviews was to practice interview style. These interviews were tape recorded and shared with supervisors to gain additional feedback.
Recruitment of Participants

For parents who resided together, a joint letter of invitation, along with a separate information sheet and consent form for each parent was sent. For parents who resided separately, an individual invitation letter, information sheet and consent form was sent to the injured parent. Injured parents were also sent a sealed envelope containing an invitation, information sheet and consent form for their ex-partner. Injured parents could then forward this envelope to their ex-partner if they wished. After both consent forms had been returned, the researcher contacted the non-injured parent by telephone to arrange a suitable time for interview.

Informed Consent

Injured parents were asked to give consent for the researcher to access their medical and neuropsychological notes in order to gain background information such as the date, type, site and severity of their injury. They were also asked to give consent for their partner's participation in the study. Non-injured parents were asked to consent to their participation in an interview. Before the commencing these interviews, participants were asked to sign a second form recording their consent to the taping of the interview.

Response Rate

Over both sites a total of 25 potential participants and their partners were identified. 12 couples returned consent forms indicating their wish to participate. Of these 12 couples, 10 of the non-injured partners were interviewed. In one case a participant who had earlier consented to participate withdrew, prior to arranging an interview. No reason was given for this withdrawal. Time constraints precluded the participation of a second individual, as their consent form was returned late in the relatively restricted timescale of the project. Details of demographic and injury variables of respondents and their partners can be found in Appendix one.
Interview format

Individual semi-structured interviews were conducted. At the beginning of the interview participants were reminded of the purpose of the research and were asked to describe any details of their partner’s injury and family composition that they felt it was important for the interviewer to know. This was done in order to facilitate the flow of participant’s subsequent narratives and allow the interviewer more ease of understanding, as pilot interviews revealed that participants frequently had to interrupt their narrative to explain background factors. It was also anticipated that details of their partner’s brain injury may be of significant concern to respondents so it was felt appropriate to allow participants space to voice these concerns at the outset. These introductory narratives lasted from 5 to 15 minutes.

The second section of the interview was opened by the question, ‘Thinking back to how things were before the injury and how they are now, do you think the injury has affected the type of parents you and your partner are?’ A closed question was used as the researcher did not want to presume that the injury had had an impact on parenting. This was followed by questions such as ‘how do you mean?’ and ‘in what way?’

Care was taken for interviews to be as open as possible, conversational in nature and to be guided by participants’ concerns. The use of an interview schedule composed of broad questions based around key areas of interest was also utilised. This was done to allow the interviewer to focus the interview on the topic of interest. Use of such a guide may also be particularly suitable for novice interviewers as they afford greater confidence and ability to attend fully to participants’ narratives (Charmaz, 2006). In accordance with grounded theory principals, the key topic areas covered evolved during the course of the research. A list of interview questions is given in Appendix three.
The interview guide was, however, utilised in a flexible manner. Questions on the guide were used to stimulate new areas of discussion when others were exhausted and were not asked if the topics had been covered spontaneously by participants. The priority in interviews was to explore participant’s perspectives and follow up areas raised by participants rather than to adhere strictly to the schedule. Follow up questions and prompts included questions such as ‘can tell me more about that?’ ‘How did you deal with that? ‘Did that change over time?’ Interviews, therefore, assumed the form of a ‘directed conversation’ (Charmaz, 2006).

Interviews lasted from 1 hour 15 minutes to 2 hours and took place between March and June 2006. Seven interviews were conducted in participant’s homes, two were conducted in participant’s work places and two were conducted in the researcher’s office at the Department of Child and Family Mental Health.

**Glasgow Outcome Scale - Extended**

The Glasgow Outcome Scale - extended version (GOSE) (Wilson et al, 1998) was completed by non-injured participants on their partner’s behalf. The GOSE is a standardised measure of recovery from brain injury and was employed in order to describe and contextualise the sample. The GOSE is an extended version of the Glasgow Outcome Scale developed by Jennett and Bond (1975) and the two scales are the most widely used measures of outcome after traumatic and non-traumatic brain injuries (Wilson et al, 1998). The GOSE is delivered by means of a standardised interview and is intended to overcome some of the shortcomings of the original scale by giving a more sensitive measure of outcome.

The GOSE assigns patients into one of 8 clinically relevant overall outcome categories on the basis of their own, or a relative’s report of their functioning in 8 domains such as work, social activities and family relationships. The GOSE has been found to have adequate reliability (Wilson et al, 1998) and correlate
adequately with other measures of outcome (Wilson et al, 2000). A copy of the GOSE can be found in Appendix three.

Information Regarding Injury Characteristics

Additional information regarding participants' injuries was accessed from neuropsychological notes. Details of these can be found in Appendix one.

Data Management

All interviews were audio taped and transcribed verbatim by the researcher. Significant pauses, non-verbal gestures and marked changes in intonation were also indicated on transcripts. See Appendix three for a sample of interview transcription. Identifying data were removed from all electronic copies and transcripts were assigned a code number before being imported into the qualitative data analysis software package, NVivo Version 2.0.

Ethical Issues

Ethical approval was obtained from a local research ethics committee. The main ethical issues identified to be pertinent to the present research were informed consent, potential distress to participants, confidentiality and disclosures.

Informed Consent

It was made clear to participants that their decision whether or not to take part in the study would not affect the clinical care that they or their families received. Participants were free to withdraw at any time and were informed at the start of interviews that tapes could be wiped and omitted from the analysis at the end of the interview if they chose.
Information and consent sheets for injured partners were approved by a Chartered Clinical Neuropsychologist for their suitability to the target population. The injured partner’s capacity to consent was confirmed by the Neuropsychologist who had previously worked with and assessed the injured partner.

**Potential Distress to Participants**

It was acknowledged that the topics discussed in the interview may be distressing to participants. The researcher viewed the acquisition of data as a secondary concern and the safety and comfort of participants as primary. Consequently, interviews were paced in order to maximise comfort. It was made clear to participants, both verbally and in writing, that they could end the interview at any time. Participants were given the researcher’s contact details and it was made clear that they could contact the researcher to discuss any issues raised in the study.

**Confidentiality and Disclosures**

Participants were informed prior to the interview that confidentiality would be maintained except in circumstances where the interviewer was significantly concerned for the well-being of the respondent or others. In such circumstances the interviewer would be obliged to discuss her concerns with the respondent and request their consent to contact the appropriate agencies. If concern was sufficient, however, the interviewer was aware of her obligation to break confidentiality without consent if necessary.
Data Analysis

Immersion in the data

Initially interviews were listened to repeatedly and transcripts read and reread to increase familiarity with the data.

Open coding

Open coding constituted the first stage in analysis and consisted of line-by-line analysis of the data, where conceptual labels were attached to each line of the transcript. In order to promote conceptualisation rather than description and sensitise the researcher to actions and process factors in the data, these codes typically took the form of gerunds. The aim of these codes was to label, break up and describe the data in order to permit further sorting and the making of comparisons. At this stage in the analysis it was possible for each line to have several different codes attached to it, reflecting the multiple potential meanings of each section. An example of open coding is given in the Appendix three.

Development of Initial Categories and their Relationships

Throughout the analysis open codes and the incidents they conceptualised were frequently reviewed and compared to one another. This allowed conceptually similar codes to be identified and clustered together, forming provisional categories. These categories subsumed several lower level codes, generating a more abstract understanding of the data.

These provisional categories were further developed by re-examination of the incidents comprising them. Incident was compared with incident in order to determine the defining properties and parameters of the category which distinguished it from other categories. Repeated inspection of the data resulted in revisions of category labels and the re-assignment of incidents to categories as the properties of categories emerged and were defined. Through this process of constant comparison, some salient differences between
different examples of a category also emerged, provoking the splitting of some categories into subcategories.

As categories emerged, previously coded transcripts were recoded as the researcher became sensitised to emergent categories and ideas. Newly identified examples of categories were then compared with previous incidents to further delineate the properties of categories. Consequently, categories became gradually more defined in terms of their properties and their constituent subcategories as analysis proceeded. Throughout coding tentative relationships between categories and subcategories were also documented in memos and diagrams as they became apparent.

**Memos**

Memos were created and utilised throughout all stages of analyses. Early memos, mainly written during immersion and open coding stages, were used to document ideas, hunches and thoughts about the data as they occurred to the researcher. As analysis proceeded, memos were utilised to document and describe the emergent categories, highlight gaps in these categories and spark ideas for further development, either via re-analysis of the data or via future interviews. Memos were also used make comparisons between categories and subcategories in order describe their properties and dimensions and to hypothesise possible links between categories.

**Theoretical sampling**

In grounded theory research data analysis and collection occur concurrently. As analysis proceeds, further data gathering is analytically driven and geared toward filling in gaps in the evolving theory. Specifically, data collection is geared toward refining the emergent categories and their properties until no new properties emerge. Strauss and Corbin (1998) advise that theoretical sampling can be accomplished by purposively sampling amongst groups of participants whose experiences are most likely to highlight
variations in categories or by modifying interview questions. Strauss & Corbin (1998) concede that for practical reasons most research involves the latter strategy, rather than the former. They caution, however, that this truncated methodology will make it more difficult to achieve theoretical density and generates a limited version of grounded theory.

The present study utilised a convenience sample comprising almost all consenting eligible clients of the neuropsychological services in two geographical areas. As such true theoretical sampling was not possible. Instead, interview questions were repeatedly modified in order to elucidate the properties of emergent categories. See Appendix three for a list of interview questions.

**Development of a Core Category**

After all interviews were completed and emergent categories and their properties had been developed, analysis turned to defining an overall framework describing categories and their relationships to one another. At this stage, memos describing categories were reread, compared and sorted in order to elucidate the relationships between categories. A set of memos was written describing the main ‘story line’ of participants’ narratives (Strauss & Corbin, 1998).

From this review of the data, several principal categories emerged which seemed to encapsulate what was happening in participants’ accounts. The links between these overarching categories and emergent lower level categories the were explored and checked for how well they fitted the data using memos, diagrams and by reviewing transcripts. The researcher then sought to relate these principal categories to one another and from this a key theme or core category emerged which seemed to encapsulate the experiences of participants. The researcher then sought to explore the links between the core and principal categories and the core category was used as a central organising element to build a formulation of the participants’ experiences.
Trustworthiness

It has been argued that the traditional criteria for quality espoused in quantitative research, such as validity and reliability cannot be applied in their original form to qualitative research (Lincoln & Guba, 1985). As qualitative research must, however, establish its trustworthiness to the reader, alternative criteria for quality which adapt the traditional cannons of quantitative research have been developed by authors such as Lincoln & Guba (1985). These authors state that the trustworthiness of qualitative research can be defined by criteria such as credibility, transferability, dependability, and confirmability. As such, strategies aimed to enhance the trustworthiness of the qualitative enquiry have been developed, some of which were incorporated in the design of the current study.

Generation of an Audit trail

An audit trail of analysis was created comprising interview schedules, transcripts, post interview observations, sequential versions of coding and memos detailing analytical insights, the generation of categories, relationships between categories and the evolving revisions of the theory.

Use of a Second Rater

Two Clinical Psychologists, both working in Child and Family Mental Health Services reviewed two of the initial transcripts each. They identified general themes contained in the data which were then compared to categories developed by the researcher. This was done to establish that the account produced appeared credible, suggest refinements to emerging categories and sensitise the main researcher to neglected analytic areas.
Member Checking

It had been originally planned to undertake a member check after the completion of data analysis. Unfortunately, time restrictions did not allow for this to be done prior to the submission of this thesis. It is, however, hoped that this can be done at a later date to enhance the credibility of results.

Reflexivity

A constructivist version of grounded theory acknowledges that the researcher, their experiences, professional and personal background and prior assumptions shape and influence coding and the resultant theory generated. Generating an awareness of and attending to one’s own experiences and values, therefore, constitutes an integral part of the research process (King, 1998). Lincoln & Guba (1985), for example, argue that the taking of a reflexive stance underpins the trustworthiness of an enquiry.

To this end a reflexive diary was used to record and explore the researcher’s thoughts, impressions and emotional reaction to the data gathered throughout the project. Specific thought was also given to how the researcher’s aims and background influenced the developing theory. A discussion of the researcher's perspective can be found in discussion chapter.
Results - Descriptive Analysis

Emergence of a Core Category: Becoming the Superordinate Parent

The present study explored the impact of a parent’s acquired brain injury on parenting and parent child relationships. This topic was explored by conducting semi-structured interviews with parents whose partners had sustained a brain injury in the last 6 years. A core category representing the central phenomenon of the data emerged and was labelled ‘becoming the superordinate parent.’ This category describes the shift in the injured and non-injured parent’s parenting roles, relationships and expectations as the injured parent ceases to enact their previous parental role and appears to shift toward a more junior parental status. Reciprocally the non-injured parent is hypothesised to assume more authority within the family and begin to occupy the role of lead parent. All the other main categories seemed to be closely related to this phenomenon and this concept forms the core of the analysis described in this chapter.

The analysis proceeds with a discussion of the three main categories which constitute the shift toward the position of superordinate parent. These are ‘loss of a capable parent,’ ‘taking charge’ and ‘children selecting a superordinate parent.’ A fourth category ‘regaining a parenting role’ which describes a move away from the role of superordinate parent, back toward a more equal status is also described. The main categories are themselves comprised of a number of subcategories, which are again comprised of a number of lower level sub-categories, which have been termed ‘themes’ for clarity in the following section.

This chapter outlines and describes each category and its composite subcategories and themes in turn, drawing on illustrative quotations from participants. The organisation of the chapter into main categories and constituent subcategories is shown in the diagram. More detailed diagrams of each main category and its constituent subcategories and themes are given in Appendix two.
Figure 3.1: Overview of the Structure of the Descriptive Analysis

Quotations in the text are followed by a number indicating the interview from which they are derived. Names have been removed from the text and substituted with an indication of the individual’s relationship with the participant, e.g. son, daughter, partner, contained in curved brackets. For families with two children of the same sex, children are identified by their position in the family e.g. youngest and eldest. Square brackets are used to provide the reader with contextual information gained from other sections of the interviews and transcription notes are placed within braces. On some occasions non-essential information such as repeated ‘ehms’ or repetition of children’s names have been omitted from quotes for clarity, this is indicated by a series of periods.
Main Category 1: Loss of a Capable Parent

One of the major ideas to arise from participants’ narratives was their perception of deterioration of their partner’s previous parenting capabilities and involvement. These difficulties enacting their former parental role also seemed to be accompanied by a loss of their previous position within the family. Participants described a shift in their appraisal of their injured partner as they ceased to see them as an equal and reliable co-parent, but instead as a dependent or childlike figure within the household.

Subcategory 1: Detachment from a Parenting Role

Participants described their partners as becoming ‘detached’ from their previous parental role and decreasing their involvement with their children post injury. Instead of taking an active parenting role, participants described their partners as becoming distant, uninvolved figures within the household and reducing their engagement in both social interactions with their children and practical parenting responsibilities.

‘Yeah there was a short period of time just after the accident that, it was almost like he was detached from her [daughter] and me, emotionally. He wasn’t detached from us physically and he did interact with us. You know and he would speak and bla bla. But I suppose there was this period time when he had a bit of emotional detachment.’ (Participant 7)

Participants’ descriptions displayed a good deal of variation in terms of the course and duration of these difficulties. Generally, more pronounced difficulties appeared to occur earlier in the post injury period, with a gradual improvement over time. Two participants, however, described a marked ongoing disengagement. Participants’ accounts also varied with regard to the extent of these difficulties. At the more severe end of this spectrum, participants described their partner as showing little interest in their children and withdrawing from most interactions and parenting responsibilities.

‘At Christmas times he has just absolutely no interest in [the children opening presents]. I would say probably this last year, which is about five years after his accident, he is beginning to be a wee bit, a wee
bit more interested but I found that hard. The fact that he just never managed to show any interest in what they were doing.' (Participant 3)

'But when the injury came, she got home she'd just no interest toward them [the children], absolutely no interest. I mean she would speak away to them like that but she wouldn'ae worry about them.' (Participant 5)

In some accounts, however, these difficulties appeared to take a less extreme form. Rather than a marked disinterest and withdrawal, some participants described their partner's difficulties more as a loosening of a previous automatic emotional connection to their children and a disruption to the previous flow of affection.

'[Before the injury] he would naturally just pick the bairn up and give her a kiss and hug. And he would naturally give me a kiss if he was going out the door. And it was almost like he had forgot, he forgot how to do that for a while...... You know like, not naturally kinda tickling her, not naturally playing with her.' (Participant 7)

Such participants described their partners as continuing to carry out practical care tasks with their children, but in a relatively emotionless way. They described their partner's interactions as becoming stilted and lacking in their previous level of emotional involvement.

'Ehm but there wasn't the same input, it was ehm, diluted cos she was distracted, so the making of a nice meal and trying to encourage them to eat decent food, she would just chuck chicken dippers in the oven and that's what they would live on for months, so there was no effort involved, or no imagination.' (Participant 4)

'Last winter [after the injury] he built a snowman and this snowman was 7 foot tall. It had arms and legs and it was like, it was like an ice sculpture, you know it was perfect. And this year the snowman me and (eldest) built was a short fat thing, with a wonky nose sort of thing but me and (eldest) had great fun doing it. Whereas last year (husband), (husband's) whole afternoon was spent making this snowman, whether (eldest) wanted to or not. Do you understand the difference?' (Participant 1)

These parents were described as going through the motions of parenting or 'doing a job' (participant one). Although they continued to interact with their children and attempt to maintain something of their previous role, their interactions appear to lack the fun and mutual engagement which had marked their interactions with the children prior to their injury.
For the most part, participants described their partners as failing to engage with their children, either emotionally or in a practical sense, rather than actively rejecting them. Only one participant described their partner as actively trying to minimise their contact with their children. Certain participants also emphasised that they felt their partners' difficulties were as much related to difficulties with self-initiation or difficulty expressing affection as genuine lack of interest.

'I can't say doesn't take an interest, in his way he takes an interest. He's always he deep down he takes an interest but it's not in a way that the boys would be able to see that he is interested.' (Participant 3)

'He wasn't unwilling but he just needed prompting.' (Participant 10)

Whether attributed to a lack of interest or difficulties with self initiation, injured parents were frequently depicted as becoming passive and socially withdrawn. In some accounts they appeared to exist at the edges of the household and take the role of uninvolved observer, rather than active family member or parent.

'But (husband) was actually, he didn't say a great deal anyway, he would never, when the kids did come downstairs he would never say a great deal he would just sit quietly on the sofa and watch the tv and leave them to their own devices. (Participant 6)

Their partner's withdrawal from emotional and practical parenting responsibilities was often described as one of the most difficult aspects of the changes in their injured parent. Participants also made various attributions regarding the cause of their partner’s emotional distance and reticence to engage socially with their children such as tiredness, impaired self-confidence, being absorbed by the emotional demands of adjusting to their own injury or as a direct cause of their injury. For the most part, however, participants described becoming confused and frustrated, particularly if these difficulties carried on for some time, as they observed their partners shifting from active independent parents, to a passive and withdrawn position.
Subcategory 2: Loss of Parenting Competence

In addition to describing their partners as ceasing to engage to various extents in parenting, participants also described their partners as experiencing difficulties managing parenting tasks when attempted. This emerged as a second, distinct subcategory as it focussed on the injured parents' perceptions of their partner's difficulties coping in a parental role when attempted, rather than their reticence to engage in this role. Two main themes emerged in this area as participants described the impact of their partner's cognitive difficulties and increased irritability. Both explicitly and implicitly, participants' narratives conveyed a sense of their lack of confidence in their partner's parenting as they described their partner as struggling under pressure and becoming increasingly dependent. This was most pronounced when discussing the period closest to the injury.

Theme 1: Impact of Cognitive Difficulties on Parenting Abilities

All participants described some deterioration in their partner's parenting abilities. Again the extent of this deterioration varied between participants and over time, as participants generally reported the most severe difficulties in the period immediately post injury. Participants described a variety of neuropsychological difficulties such as mental inflexibility, lack of imagination and speech difficulties that impaired their partner's ability to carry out childcare tasks successfully. Most frequently mentioned, however, were memory, tiredness and planning difficulties.

'Because physically he wasn't able to cope with a lively 2 ½ year old. Cos after his accident he was physically quite tired, he got tired very quickly.' (Participant 8)

'So there was a point that he wouldn't actually have been able to go to the health centre.....and go in and get (daughter's) injection because he'd probably forget what it was he was supposed to be doing and he might not, you know, remember what an injection was, you know.' (Participant 7)

'I mean to try and, for him to take the children out for the day, you know would involve so much time planning that it would take up his whole week almost just to plan, a trip out somewhere. So, when he was at home he couldn't do that just because of all the noise and everything.' (Participant 1)
Participants described these difficulties as exerting a huge impact on their partner's capabilities. Injured parents were, however, usually considered to be capable of undertaking circumscribed tasks such as changing a nappy. It appeared that injured parents struggled more when faced with tasks which placed multiple simultaneous demands upon them and required an element of planning and co-ordination, such as the challenges described by participants one and seven above.

Participants also acknowledged the challenges and complexities of 'coping' with their children. For the injured parent, it appears that parenting becomes a hugely effortful and exhausting exercise, as the sequelae of the injury interact with its inherent demands. This is demonstrated in the excerpt below where participant two describes her husband's attempts to care for their son whilst she is in hospital having their second child.

'So as the weekend got on, come the Sunday, (husband) could, you could hardly understand what (husband) was saying. He was so shattered, obviously his speech [deteriorated] ..... an a'body noticed it, ken, we a' noticed it. And then, I can, I think it was my mum that took (eldest) that kind of night. So that he just had to see to himself the next day because you could hardly understand what he was saying.' (Participant 2)

Participant two was unclear about the extent to which her husband had coped, as she later pointed out she had no way of knowing what had happened in her absence. He does, however, appear to have coped to a certain extent, for a limited period. More frequently, however, particularly in the early stages of recovery, participants described their partners as collapsing under the weight of the demands of parenting. This appeared to occur most commonly when unexpected or multiple demands were placed upon the injured parent.

'Just because he can't think independently outwith a plan and he is getting better, it is getting better but if something changes, that isn't on the plan I still don't know how he would get around it. You know because he doesn't, he can't, the thought process isn't there. Or, you know he might not know what to do in certain situations still..... [When son trapped fingers in a car door] He just stood there, we were in a car
park and I just pulled up and seen (eldest) standing with his hands still in the car door and (husband) just standing beside him.' (Participant 1)

'If anything that happened out of the ordinary, he just couldn't deal with it and that was his brain process, it was obviously to do with the brain injury. He couldn't process information and deal with any new situation... you know the thing like a child being sick on the sofa ....that happened, and he couldn't deal with it, he just didn't know what to do. Because it wasn't that he didn't know, it was that he couldn't clean up the mess and deal with the children at the same time.' (Participant 10)

From a neuropsychological standpoint these difficulties seem to be related to executive functions, for example, planning, divided attention and mental flexibility. As participant ten points out, her husband may have been able to deal the situation if it had not required him to do more than one thing at a time. As these examples demonstrate, parenting often calls for a more co-ordinated response. When faced with challenges they felt unable to meet, injured parents were perceived to ‘overload’ (Participant six) and were described as experiencing intense anxiety, agitation and becoming incapable of formulating a response to the problem. Consequently, the injured parent often appeared to freeze or collapse under pressure.

In such situations, injured partners were described as frequently calling on the non-injured parent to step in to rescue the situation. Participants, therefore, also described their partners losing their confidence in their own abilities as becoming increasingly dependent on them when dealing with their children.

'It was when the kids were saying something he would kind of look with that look on his face of 'what should I do, how do I, what do you want me to say here?' He had lost that much confidence that he wasn't sure what to say for the best. So he would look and panic. (Participant 6)

'It's that she cannae decide whether it is okay to let (youngest) go to the pictures, you know, so rather than make the decision she would rather I made the decisions whether she can go or not.' (Participant 5)
Theme 2: Increased Irritability

A second major theme to emerge from participant’s accounts of the changes in their partners’ parenting skills and style was that injured parents often displayed increased irritability and anger when interacting with their children.

‘And he is not now, he is a much more {{ 1 sec}} he is kind of, he is more short tempered than he ever was before, or moody or, and he never ever was before, he was a very level kind of person. Which makes it difficult when you have a toddler in the house.’ (Participant 8)

‘But in the very, very beginning, it was just horrendous, ken he just didnae have nae patience, couldnae dae nothing and he just got frustrated and angry and stuff. And I sometimes still hear him to this day like, sort of like raised kinda voice, ken, kinda like ‘that’s!’ [raises voice] to the kids and stuff, and I think there’s nae need for that, ken it was a bit uncalled for.’ (Participant 2)

Although all participants described an increase in irritability, demonstrated by increased shouting at the children, this varied widely between participants and over time. The most extreme difficulties seemed to occur earlier in the post injury period and varied in intensity between participants. At the more extreme end of this spectrum a few participants reported daily and intense arguments, whilst others reported less frequent difficulties. In all cases these difficulties centred on verbal outbursts and no participant described physical aggression towards their children. Several participants reported this difficulty, however, to be the most enduring and marked change in their partner’s parenting. Some participants linked this change to a more global personality change in their partner.

‘But oh me, she was willing to fight with a ‘body you know, she would have fought a’ one when she first got out of hospital, and she was never like that.’ (Participant 5)

‘He was very patient, its really affected him with the kids because out of the two of us (husband) was mair the laid back kinda person, I would have aye been the mair firey character out the two of us, opposite like that but ken, that happened to (husband), his personality changed.’ (Participant 2)

Other participants described their partner’s increased irritability as being particularly apparent during interactions with their children. Such participants referred to the, sometimes, stressful nature of dealing
with their children and some portrayed their partner’s angry responses as an exaggerated form of a normal reaction to these frustrations.

‘You know she wants something that she can’t have or you know, she wants an ice lolly at 8 o’clock in the morning, sometimes she does. You know these kind of things it’s difficult obviously for her to understand that she can’t have these things and that’s. Trying to explain to her is quite difficult, but I find it difficult too. You know he just I suppose finds it more difficult or gets to the point that he is becoming angry quicker than I do.’ (Participant 8)

From participants’ accounts it seems that, for the brain-injured parent, who may have a decreased frustration tolerance, parenting provides a wealth of annoyances that may trigger angry outbursts. Other participants also explicitly linked deterioration in their partner’s general parenting skills to an increase in shouting and loss of patience.

‘It would be just like playground discussion. You know, ‘I’m not eating it,’ ‘you will eat it,’ ‘no I’m not eating it,’ ‘you will eat it,’ ‘no I’m not eating it,’ ‘oh get stuffed,’ or something. Instead of thinking about it and trying to be one step ahead of them and whatever, and manipulating them, there was none of that, she’d just simplified thoughts, it was all too much.’ (Participant 4)

‘She couldnnae deal with it, she couldnnae deal with it and the only way she could deal with it was like to try and stamp her authority. She was trying too hard to stamp her authority and she would just end up bawling and screaming.’ (Participant 5)

It seems parenting may frequently place the brain-injured parent in challenging positions and, as discussed earlier, these parents may have reduced access to their previous fine-grained parenting skills. Participant four, for example, describes his wife as previously having had a variety of strategies to manage her children which are no longer available to her. Consequently, injured parents may struggle more than other parents to meet the demands placed upon them, increasing their frustration. Any reduction in their behavioural repertoire may also increase the likelihood of using shouting in order to resolve the situation. It, therefore, seems that this process may bear some similarities to that described in the previous section where injured parents were described as collapsing under pressure, as they no longer have easy access to their former parenting skills.
**Subcategory 3: Having this Extra Child**

The final subcategory in this section centres on the non-injured parent's changing perception of their injured partner's status within the family and the parenting dyad. This emerged as a separate and substantial area as participants reported perceiving a shift in the dynamics of their relationship with their partner. Participants described ceasing to see their partners as full, equal partners, capable of assuming an active parenting role. Participants instead viewed their partners as increasingly dependent and unable to assume responsibility, with nine of the ten participants directly likening their partner to an extra child in the household.

Participants' perceptions of their partners as dependent seemed to stem partly a sense of their partner's new dependency, vulnerability and need to be cared for.

'Because he's not living here [since the separation]....I don't feel as if I've got to, ehm look after him anymore. And I suppose while he was here it just felt like having another child, to make sure he got up and got dressed, done things.' (Participant 1)

'You didn't have the confidence in him to do things because I think of how bad he was [immediately following the injury] and we never expected him to recover. To then go from having to take him to the toilet to doing all these things.' (Participant 6)

In other accounts the injured parent's withdrawal from family and their failure to enact their previous role as a capable adult and active parent also seemed to contribute towards this shift in appraisal.

'Yes, he didn't really have a great deal to contribute to, the family, didn't really, we just muddled on and he was there. We got on as much as normal. But had to deal with his this child [injured partner] in theory.' (Participant 6)

'Well instead of being dynamic and an emotional lead she sort of became a child herself.' (Participant 4)
For other participants, the observation of their partner’s increasing irritability and difficulties coping with their children in calm manner seemed to reinforce the impression of their partner as childlike and lacking in maturity.

‘Either they wouldn’t eat their tea, they wouldn’t do what they were told, either it was all too difficult or she was just too, or she would let them run off, just go wild or she would respond to them as if she were a child rather than as a caring sensible parent.’ (Participant 4)

‘There was big argument now you know what it was like? It was like (wife) was a kid an’a’...... Well it was, (eldest) was 14, (youngest) was 11 and it was like (wife) was 12, quite honestly, that was what it was like. An’ (eldest) was probably more mature, not all the time, but a lot of times. (Participant 5)

Participant’s changing view of their partner, therefore, seems to occur partly as a consequence of the other more tangible losses in involvement and skills, as their difficulties enacting their previous role appear to contribute towards a change in the parent’s perceived status within the family. Such a shift in appraisal from adult giver of care to childlike recipient of care represents a huge alteration in non-injured parent’s perceptions and this transition to a childlike status constitutes another aspect of the loss of a capable parent.

‘Yeah, we weren’t equal anymore and I was treating him like a child because he was acting or behaving like one.’ (Participant 1)

Participant one directly refers to a loss of equality, and it seems that the changes in the injured parent have resulted in a change to the pre-injury family dynamic, wherein the injured parent now relies on non-injured parent whilst the non-injured parent ceases to feel able to rely on their partner. Consequently the injured parent appears to slip down the family hierarchy to a dependent position, placing the non-injured parent in a superordinate role.
Main Category 2: Taking Charge

A second major theme to arise from the narratives concerned participants' descriptions and perceptions of their transition to a new role within the household, wherein they assumed control of the family, their partner and their children.

Subcategory 1: Taking Charge of the Family

One of the most striking features of participant’s narratives was their description of being thrust into a position of taking charge of and assuming sole responsibility for the family. Two main themes emerged in this area. Firstly, participants described adopting and accepting a new role as manager of the family. Secondly, participants described the emotional and parenting consequences associated with this new role.

Theme 1: Assuming Ultimate Responsibility

Participants described facing multiple demands, such as work and caring for the injured partner. It was, however, participants' descriptions of their increased parental responsibilities, particularly in terms of the practical care and supervision of their children which pre-dominated.

'Well cooking, cleaning, ehm discipline general parenting. Beforehand I would just come home and ehm I would be looked after, you know, which was a bit of an adaptation, [since the injury] I would have come home and do more and more that I expected.' (Participant 4)

Participants described their partner’s withdrawal from an active parental role as forcing them, in the absence of another alternative, into a position of having to take up the 'slack,' (Participant 10). Participants emphasised that prior to their partner’s injury the responsibilities of parenting and management of the family had been a much more shared responsibility. Participants reported that after the injury, however, they felt they had to carry these responsibilities single handedly, without the support of their partner. In some ways the non-injured parent begins to function as sole parent, as they are left in a position where they feel they must continue to care and ensure the well being of the children on their own.
'Yes, uhuh, everything you did you had to think for yourself, there was no discussing anything. (Husband) wouldn't have taken it in and been able to think about it enough to give you and ......... That was the hardest part was, you were on your own.' (Participant 6)

'Nobody's questioning, you've not got a partner or somebody there that's saying, is this right, cos (husband) is nae. I mean even if we'd not stayed together, or we'd divorced or anything, he would still have some input, presumably.' (Participant 3)

All participants described a substantial increase in their parental responsibilities post injury. In addition to taking on day to day individual tasks such as cooking and supervising the children, participants also described taking on the role manager of the family. They described feeling ultimately responsible for organising and making decisions for other family members. As they assumed these responsibilities, participants also described developing an awareness that the well being of the family lay in their hands. Participants described feeling ultimately responsible for their children and spouse and having an awareness that the buck stopped with them.

'Well he couldn't be responsible so I had to be. (Participant 9)

'So I suppose, I'll tell you my health has actually become a big issue because if something was to happen to me what would happen to [the family]? (Eldest) is old enough to stay herself but who'd look after them, who'd look after (wife). (Wife) couldn't look after herself and she would struggle to look after the kids herself as well so ever since, my health has become more of a priority.' (Participant 5)

Consequently, participants described an acceptance, or at least an acknowledgement, of their new role. This was often couched in terms of dealing with the situation in the here and now and the need to get on with it.

'Maybe the practical person in me, that's just the situation we were in, so that's what we do and I don't think I ever thought about it being different to what it would have been if he didn't have the accident. Cos he did have the accident and that is what we had to deal with.' (Participant 8)

'I don't know if you have got kids yourself? [Interviewer shakes head]. You have to, you can't afford to sit round and mope and think about your problems there just isn't time for that, you just have to get on with it.' (Participant 10)
Theme 2: Feeling Burdened by Ultimate Responsibility

As well as describing their new role and their, sometimes, reluctant acceptance of it, participants also described the perceived costs and consequences of their new position in the household, as they described perceiving a 'burden,' (Participant 4) associated with taking on overall responsibility for the family. At times these responsibilities felt overwhelming and the participants described feelings of anxiety and inability to cope with their new found responsibilities.

'I thought no way is this happening, I mean how am I supposed to cope with this? And I hadnae even had (youngest) yet neither at this point and I just thought no way!' (Participant 2)

'I suppose you just kinda, aye, you felt absolutely exhausted and thought when is this ever gonna end?' (Participant 4)

Most significantly in terms of parenting, half of the ten participants interviewed described their extra responsibilities and new role as the ultimate manager of the family as impacting on their sense of competence as parents or ability to be a 'proper mum,' (Participant one), as participants described questioning and doubting their own parental abilities and decisions.

'I'm giving (husband) advice and I don't even know if I'm a good parent myself.' (Participant 1)

Participants self-doubt over their own parenting performance seemed to occur mainly in the context of their ability to offer their children affection or spend time with their children, particularly time spent engaged in fun activities, rather than practical care. These pressures were described as forcing their own parenting to become rushed and somewhat perfunctory.

Well it's a big house, I would be remote physically[from the children] and cos I would be in another room [carrying out domestic tasks] and just [removed] emotionally in terms of general chit chat and having a joke, getting a hug or playing games. (Participant 4)
I would say on a scale of 1 to 10 I would give myself a 4 [for being a dad]. I probably if I could go through the whole thing again, nay that I would want to, would do things differently, dinae ask me what, but I would probably be try and be there more and have more to do with them, aye a lot more to do with them.' (Participant 5)

These participants describe their new responsibility for maintaining the overall smooth running of the household as compromising their abilities to fulfil their previous roles within the family. Clearly certain shaping factors were influential in the creation of this situation and perspective, as only 50% of participants described this. It is likely that the extent of their partner’s parenting difficulties and withdrawal may be influential here, as the five participants who described a possible deterioration in their own parenting also described the greatest ongoing (or recently remitted) degree of difficulties experienced by their partners.

**Subcategory 2: Taking Charge of your Partner’s Parenting**

The previous subcategory discussed the idea that the non-injured parent begins to assume overall responsibility for the family and its organisation. A second related idea arising from participants’ narratives was that they no longer saw their partners equal partners in parenting and described a shift in roles wherein they assumed the role of lead parent and began to assist and manage their partner’s parenting.

**Theme 1: Doing the ‘Telling’**

To some extent non-injured parents seemed to assume a role of expert parent who instructed their partners regarding what to do with the children and how to do it, described as doing the ‘telling’ (Participant one). Their partners, in contrast were sometimes described as a relatively novice parents who required instruction in both childcare and child behaviour.

'I had to explain that to him that, you know, that she needs to be allowed to pull her toys out and play with her toys because you know there is no point her having them if they have to sit tidily on a shelf. You know I had to explain all that to him.' (Participant 7)
In addition to tutoring and coaching their partner, participants also described assuming responsibility for managing their partner’s interactions with their child and parenting responsibilities, providing their partner with explicit instructions of how to meet their responsibilities as parents.

I would leave explicit instructions for (husband) about you know, I would, like if he was having to give her, if they were having something for their lunch, I would actually take it out and put it on the side.' (Participant 7)

The night before he [injured partner] would say ‘what needs to be done tomorrow,’ ‘well these are the things that you need to do.’ The kids have got drama or swimming or whatever, I’m working late and these are the things that need to be done and he would write them down in a list. 3 o’clock pick up the kids, 5 o’clock swimming lesson, whatever.' (Participant 9)

As well as coaching their partners in how to care for their children participants also described telling their partners how to interact with their children. The participant in the quotation below described her attempts to smooth a disagreement between her children and her partner by explaining to her partner how she thinks how he ought to have behaved and handled the situation.

Its finding a balance, of speaking to them both, perhaps together and maybe saying ‘okay, yeah you[child] should not have done that but (husband)[you] shouldn’t have [shouted] there’s a different way of handling it.’ But that’s something I think we have still yet to, to get to....I think I could probably start now, if something happened I probably could, bring them together now and start to discuss it that way but up till now it has been just this go between, go to that side and speak to them separately. (Participant 6)

Here, the non-injured parent appears to adopt a parental stance over both her partner and her children as she considers sitting them both down together to discuss their behaviour. In this extract both the children and the injured parent are placed on an equal footing as the non-injured parent appears to admonish both child and parent for their earlier behaviour and attempt to help them find ways of improving it. Other participants also seemed to adopt a similarly authoritative stance over their partners as they attempted to instruct them. This seemed to occur particularly in the context of the injured parent being seen to lose their patience with the children and participants’ narratives often described intervening in disputes by adopting a stance of parental authority and telling the injured parent off or overruling them.
'Ehm, and I would sort of jump in and say leave him, leave him.' (Participant 3)

'I usually said something, said something to (wife) like, 'they were trying to tell you something (wife), there is no need to tell them to shut up.' (Participant 5)

Consequently the non-injured parent seems to assume a certain amount of control of the injured parent’s interactions with the children as they instruct, oversee and attempt to modify their partner’s behaviour. By directing their parenting in this way they appear to assign their partner the role of junior parent and underline their own position as the head of the household. At other points in their narratives this assumption of control appeared to take slightly different form, as participants described either limiting their partner’s parenting responsibilities or at other points pushing their involvement with the children. These areas are, therefore, dealt with as separate themes in the following sections.

Theme 2: Limiting Parenting Responsibilities

Participants frequently discussed making judgements of the parenting tasks their partners were and were not able to manage and adjusting the demands they placed on their partners accordingly.

'(husband) never had any say in this...... never, cos he wasnae able.' (Participant 3)

'We tried to keep as much responsibility from him as we could because he had enough to deal with, perhaps getting himself to (rehab centre) getting his bits and bobs he needed together, make sure he had had his breakfast and cup of tea before he left........Ehm he would stress out over it rather than. You would upset him and stress him out rather than, be able to deal with and sit and discuss it so it was easier to keep, just do it yourself and tell him what you had done.' (Participant 6)

These excerpts illustrate how the non-injured parent, who may perhaps have become used to doing things themselves, ceases to place the same level of parenting demands on their partners as they no longer see their partner as able to support them in parenting or succeed in these tasks independently.
This reluctance to place demands on their partner in some cases also seemed to be related to an attempt to protect their recovering partner from the ‘stress’ of parenting, as described by participant six above. Participants often seemed to take a protective role over their partner and described attempting to minimise the demands placed on them, particularly during the earliest stages of recovery in order to allow their partners the space to recuperate.

‘Because he was physically tired things like, allowing him to sleep, so I would even maybe take (daughter) away, we would maybe go out, just to make sure that he could, he could rest.’ (Participant 8)

‘It’s not worrying about their safety or him not coping, it’s more I suppose that I just worry that maybe, you know it’s a lot to ask [husband] to look after their child for a weekend.’ (Participant 7)

Participants’ reluctance to place demands on their partners was particularly apparent when they discussed the option of leaving their partner in sole charge of the children. Particularly when discussing the earliest periods of recovery, participants frequently voiced a reluctance to leave their partner in sole charge and several parents described having other family members, or paid help, supervise their partners in their absence. Again this seemed to relate to their expectations and lack of confidence in their partner’s parenting abilities and ability to cope with the children.

‘Like I wouldn’ae have been able to like leave him on his own with the kids. Ehmm he wouldn’ae have been able to look after them or stuff.’ (Participant 2)

‘It’[husband struggling to cope with baby] does happen, if I let it happen, I’ll only let it happen if I have not other choice, say if I have to go to the toilet and I’ll say (husband) you look after (youngest). And as soon as I’m gone (youngest) will start crying and (husband) doesn’t know how to stop it.’ (Participant 1)

These quotes illustrate how participants adopt a position of not only absorbing extra responsibility but also of limiting and controlling the level of responsibility allocated to their partner as they decide which parenting tasks their partner is, or isn’t able or allowed to engage in. The language used by participant one of ‘letting’ things happen, conveys the non-injured parent’s sense of control over responsibilities and parenting within the household. This participant appears to describe herself as the lead parent who
decides what the injured parent can and can’t do in relation to the children. Consequently, in addition to being a sensible strategy in the early stages of recovery, the non-injured parent’s active allocating and limiting of their partner’s parental responsibilities underlines their position as the superordinate parent.

**Theme 3: Pushing Involvement**

As well as limiting their partner’s level of responsibility, at other times participants reported pushing and prompting their partner to interact with the children. All participants reported some degree of prompting but in some accounts the level of pushing was particularly marked.

‘Yeah it was just constant. You were always just guiding I suppose just making, ehm creating situations and playing games and things that put them both, put them all into the position where we were doing things together, so there wasn’t a him and me or a him and them. bring them together so that they could play together which brought confidence, build their confidence.’ (Participant 6)

The injured parent’s withdrawal from the family appears to place the non-injured parent in a position where they feel they have to push the parent and the child together. Some participants seemed to adopt a supervisory role, arranging suitable situations for the parent and child to interact in a controlled manner. Participant 6 describes this as an attempt to rebuild her children’s, and perhaps her partner’s, confidence in their father’s abilities as a play-mate. Later the same participant describes this attempt to build confidence in more detail in relation to asking her partner to switch the shower on for their daughter:

‘just that couple of seconds when they were both alone in a room together ..... [daughter] then felt more comfortable with that, there was a bit more ease then. Or perhaps, ‘yes he is all right he can do that,’ and it was just to let the children see that he was capable of doing things for them and he was capable of thinking for himself as well so that they felt comfortable to be able to ask him, to be able to be alone with him without having to speak even. ‘oh thanks dad,’ or whatever. It was just the fact that he was ehm just little things, just little scenarios that you would put them in.’ (Participant 6)

It seems that the non-injured parent’s explicit aim is to re-build the parent child relationship. Participants described their need to ‘get back to normal,’ which included rebuilding the child’s confidence and relationship with the injured parent and re-locating the partner in an active parental role.
'So I used to encourage him to dae things like that. Just things that he would have done before in general, to kind of make things feel normal, I used to kind of push to dae.' (Participant 2)

'I don’t want (eldest) to drift away. So I’m trying to, you know, I don’t want them to lose that relationship.... [so I] get them go play with something together.' (Participant 1)

For participants, normal family life and roles appear to have disappeared post injury. They attempt to shift their partner back into a form of parental role in order to regain some sense of normality. The role they are shifting their partner into at this point, though, is remains a partial parental role as they are included when the non-injured parent allows or forces them to be. Moreover, the non-injured parent also continues to oversee these interactions, tutoring their partner and maintaining control and perhaps partially undermining their partner’s status as independent parents. The sense of normality and resumption of roles, therefore, remains a construction by the non-injured parent as they attempt to fit family members back into old ways of being, apparently hoping, that this will facilitate a resumption old roles which does not need to be forced.

For some parents there is an also an acknowledgement that pushing the child and parent together (in this case to complete a DIY job) will not facilitate a resumption of normality but that they are instead creating an illusion of how family life could have been.

‘So it was really trying to get (husband), to do stuff but also for (eldest) to try to learn a wee bit about what he’s supposed to do. And some of the time [injured partner and son]..... they would both benefit from that as well, most of the time the job wasn’t right, but it was just trying to, that process of trying to maybe make something that should have been but wasn’t going to be.’ (Participant 3).

**Main Category 3: Children Selecting a Superordinate Parent**

A third main category which arose and seemed to underscore the non-injured parent’s position as superordinate parent arose from participants’ descriptions of parent child relationships in the period post injury. This category, however, emerged from, and only applies to 8 interviews, as 2 parents of the some
of youngest children in the sample (participants 8 and 10) reported observing little change in their children's response to either parent in the post injury period.

The remaining eight participants, however, reported that to various extents their children developed a tendency to look to the non-injured parent as their main source of support. Participant’s narratives, however, displayed a large degree of variation when discussing their children’s reactions, particularly with regard to the extent of these changes. Participants’ accounts seemed to centre on two key areas; the children’s propensity to approach and engage with the injured parent and their tendency to assign them a parental role in terms of placing demands on them and following instructions.

**Subcategory 1: Trepidation**

Participants generally described their children as taking a somewhat hesitant approach to the injured parent, both during their hospital stay and upon their arrival back in the home. Participants described their children as being unsure of what to make of the changes in their parent and hence initially maintaining a distance.

'(Husband) would speak to him and get onto him but the bairn was quite wary.' (Participant 2)

'Ehm they knew it was their dad {{2 secs}}. But (daughter) she has always been the less demonstrably affectionate one and (son) loves hugging and kissing everyone and anyone and uses that to get what he wants. (daughter) has always been straighter. And she would be the one that was less huggy and kissy. You know if (husband) went to give her a hug she would be a little bit, just not sure if this was, she was comfortable just because dad had this big thing on his leg [wound from accident] and she knew that he had hurt his head and she was just as little anxious about it all.' (Participant 9)

All participants described their children as having some awareness of the impact of their partner’s injury. For most children, however, this was described as an incomplete understanding. Participants described their children as being aware that something was not right; even if they could not put their finger on exactly what it was.
'I don't think they kind of knew what was going on I think they just thought, it's a bit funny, dad is behaving a bit oddly, you know. I don't, I don't know that they particularly equated it, thought of it as a result of the accident I think they just thought dad is acting a bit funny. I don't think they understood why or what was going on.' (Participant 9)

'Cos obviously she, she understands that her dad was in an accident and she tells everybody that his brain was broken [laughs]. But obviously she doesn't understand.' (Participant 8)

From the narratives it appears likely that this lack of complete understanding makes the children cautious of approaching the injured parent and hesitant to interact with them. They appear to struggle to accommodate the changes in the parent, perhaps partly as they are unsure as to exactly what has changed, and maintain a certain amount of distance.

They would come and say, 'will daddy look like he used to do when he is back to normal?' And thing was he didn’t, in a lot of, he didn’t have any visible scars, it was just he looked different. He did, I mean he is looking better now, but there was just something that just wasn’t quite right. The children just didn’t take to him at all. (Participant 6)

Four participants (one referring to only one of her two children), however, also described a more extreme reaction in their children. These participants described a marked deterioration in child parent relationships, as children actively sought to minimise their contact with the changed parent.

'(Daughter) was always a daddy's girl and now she wouldn’t go anywhere near him she wouldn’t sit next to him, she wouldn’t.' (Participant 6)

'(eldest) and his dad were always thick as thieves. Their relationship it was very, they were very, very close, very solid and then and now it’s very distant' (Participant 1)

Factors that appear influential in shaping these children’s reactions may be the extent of their injured parent’s negative behaviour and personality change. Three of the families who reported the greatest degree of deterioration also reported a greater degree of irritability in their partners, at least at the earlier stages of recovery.
‘I mean the kids just didn’t want to [be with their injured parent] so {whooshing noise} as soon as there was any sign of arguing off they go. And they were out all night, where before they would pop back and fore, back and fore, whereas now they just [go].’ (Participant 5)

Other important shaping factors may be the age of the children involved, as the four participants who reported the greatest degree of disruption also tended to have slightly older children at the time of the injury and indeed this group included the two families with adolescents.

**Subcategory 2: Reallocating Demands and Expectations**

In addition to describing their children’s general level of comfort with the injured parent, participants also described their children as re-allocating who they placed parental demands and expectations upon. Participants described observing a shift in their children’s expectations of the injured parent as they reduced the amount of parental demands placed upon them.

‘Well if they wanted a snack or get their pack lunch made or have a bath or whatever [they would ask me] because I had been the only one that had been home. It just carried on like that.’ (Participant 9)

‘If something is broken …… (eldest) would have always gone to (husband) and then ‘daddy can you fix this?’ Not now, he’ll come to me.’ (Participant 1)

As participant nine indicates, this shift in the allocation in demands may be partially created by the injured parent’s lengthy hospital stay, which was experienced by 8 of the 10 families interviewed. Participants remarked that during this period they and their children evolved a routine and an alternative way of meeting the demands of the family. It seems that when the injured parent returns to the family their role may already be partially eroded as other family members have stepped in to fill the gap during their absence. Any attempts to rediscover this role and re-establish oneself as an active and capable parent in the children’s eyes is likely to be further hampered by the children’s awareness of their parent’s cognitive and physical limitations.
"(Husband) will say, he'll tell them to go and do their homework or he'll get on at them and they'll get it out and they'll sit and they will struggle with it and but they wouldn't go to (Husband) for help, they will come to me for help. And then (Husband) will get cross that they are not getting on with it or something........He does have the patience but they will not [ask him], its as if he doesn't, because he has had a brain injury they don't think.' (Participant 6)

'She knew he was [different], there was something slightly different about dad and sometimes he didn't get it right. And she had to come and check with me.' (Participant 7)

It seems that the children's, often partial, awareness of the injured parent's difficulties causes them to cease to be seen as a reliable source of support or instruction. Instead, they are seen as an uncertain source of authority whose instructions needs to verified by the non-injured parent.

The children's hesitation to approach their injured parent with the same level of demands appears to grow, in some cases, not only from the suspicion that they might not be met, but also from recognition of their parent as unwell or delicate.

You know, if she knew that he was in his bed having a lay down she wouldn't run through and speak to him. Which she would do now and she would have done before, ........[post injury] she would say 'where is my dad?' and I'd say 'he is lying down' and she'd say 'oh ok then' and then she wouldnae go through. She would know that he was tired and he was needing a rest or whatever.' (Participant 7)

Rather than being seen as a reliable source of support whom demands can be piled upon, the two-year-old child in the above example learns to modify her behaviour around her father. She appears to see her father as less robust, and this view seems to have grown partly from her observation of his difficulties. This view is also likely to have arisen from the instructions and information given by the non-injured parent as several participants also described telling their children to leave their injured parent alone or be careful around them.

The examples above also demonstrate how the decreasing level of demands on the injured parent is accompanied by an increasing reliance on the non-injured parent. This appears to situate the non-injured
parent in the position of lead parent and some participants explicitly described their as acknowledging their position as superordinate parent.

'At the time the kids kind of knew that mum was in charge.' (Participant 9)

For some participants, the move towards occupying a lead role was a relatively subtle one as children reallocated some demands to their non-injured parent, allocated them the final say in instructions and were hesitant to place demands on their injured parent. Other participant's accounts described a far more dramatic shift in the children's perceptions of the roles of their parents. The minority of families described a more extreme erosion in their children's expectations and a growing disrespect and dismissal of the injured parent.

'[eldest child said] Well, you've got no say in it anyway dad, it's mum that'll. Mum's the boss here so it's tough, you'll. It depends what mum says.' (Participant 3)

'It was[as] if it was, 'oh you don't bother speaking to him because he can't answer your questions, he can't'. It was as if what he said did not count, because he didn't come across as making a great deal of sense at other times, depending on how tired he was he slurred his words.' (Participant 6)

Shaping factors which seem to determine the level of the injured parent's slippage in the family hierarchy may be related to the level of change observed in the parent and the age of the children as those families with the oldest children and those who described the greatest degree of personality change and dependency in the sample also tended to report a more extreme reaction in their children.

**Main Category 4: Regaining a Parental Role**

The three main categories outlined previously relate to an initial period of change and adjustment within the family, wherein the roles of both the injured and non-injured parent appeared to alter as a consequence of the injury. Most participants also described a second process, where their family began to re stabilise and both the injured and the non-injured parent's roles once again shifted as the injured parent appeared to
move closer to their previous parental role and the non-injured parent appeared to relax their position of superordinate parent.

**Subcategory 1: Recovering the Lost Parent**

All participants described to some extent, their partners as recovering some aspects of their previous parental role and a subsequent handing back of responsibility to them. The extent of these changes, however, varied considerably between participants. Some participants, for example, reported a second major change in family roles occurring within the first year post injury. Other participants reported a much slower rate of change, occurring over a number of years, with a less complete return to the pre-injury parenting structure. Three themes emerged in this area as participants described their partner’s improving parental competence and involvement, a gradual handing over of parental responsibility and a growing adjustment by the children to their parent’s recovery.

**Theme 1: Recovering Abilities and Involvement**

All participants reported their partners as recovering some degree of parental capabilities and involvement within the post-injury period, although the extent of this varied considerably. For many injured parents, even those who were described as regaining a good deal of their former skills, the return of their abilities was gradual and was often dependent on the development of various strategies. For many injured parents the development of a clear routine appeared to aid their abilities.

'When I'm at work he runs the house, he knows ....... when the kids get home from school Friday the clothes come off, they are in the wash ready for Monday and he gets that done organised, washed, ironed so they are ready for Monday morning. Ehm, he does the cooking, he does the organising, make sure if they have homework....... he will think at night and ask 'have you got homework to do?' (Participant 6)
Other strategies mentioned by participants were memory aids, over preparing and in one case being supported by a carer. It appears that for some injured parents the parental role recovered is a modified one, where they approach a limited number of tasks in a careful manner.

'She doesn't fill up her day with lots of stuff, she limits to one or two things. Whereas before, pre-injury she could juggle a huge number of balls, work, kids, the whole thing, time management. She doesn't do any of that she keeps her life simple now, no job. Eh running the house, running the kids.' (Participant 4)

Participants also described their partners as having improved patience and decreased irritability, although no parent described this difficulty as entirely remitted.

'[It used to] get the point where he [partner] would think I have to get away from this because I am going to start to shout at her [daughter], whereas now he can spend some time reasoning with her and explaining why she can't have things that she is wanting. So in that respect he has gotten much better.' (Participant 8)

Similarly, participants reported a gradual improvement in their partner's emotional and social involvement with their children. This extent of this improvement, however varied between accounts and two participants, in particular, reported only a slight degree of re-engagement with their children, described more as 'putting up' with them (Participant 5) and a return of only a few, relatively passive, activities.

'[There are] not very many [good times]. I do sometimes occasionally, they'll sit and watch "The Simpsons" or they'll sit and watch a comedy or, on occasions, they'll sit and they will have a laugh sometimes, which is quite nice.' (Participant 3)

For the most part, this improvement was often described as occurring extremely gradually, as the injured parent slowly moved from their previous passive position, somewhat outside of the main family system and slowly eased themselves back into family life.
'I think just as he improved he would ask what we were doing and I would start and say 'would you like to come and play scrabble or something' and play with the kids. ....... And that's how, it's gradually, he would, he became and he would recognise a word and say 'oh how about putting that in?' And then it would just be as his confidence grew again, that he was able to feel that he maybe could ask if he could join in or if he could 'can I do that,' or 'I think I can do that now.' I think it is a gradual progression from him maybe where he sometimes found 'oh I'll maybe I could have a go at that.' (Participant 6)

A few participants, however, described a complete return of their partner’s emotional engagement with their child within as little as the first 6 months of the post injury period. Despite their partners’ initial difficulties and withdrawal, five of the ten participants described their partners as now being more involved and prioritising their time and relationships with their children to a greater extent than they had pre-injury.

'Actually no, because (injured parent) does a lot of other things for her now that he would not have done then. ......... Like he will make posters or they will make castles out of lavvy hole holders, stuff like that. You know he will do all that now but whereas he would not have done that then, he would have done it before.' (Participant 7)

'Yeah I mean, he has always wanted to a good dad but I think he was kind of putting it on hold until the kids were a bit older and were able to do the things that he really loves doing [sports] but I think he kind of re-adjusted and went down to lower standard for him so that the kids could join in earlier, basically.' (Participant 9)

Some participants attributed this to the increased amount of time the parent and child had spent together at home during their recovery, as participants were forced to give up or reduce their working hours. Four participants, however, also attributed this to a more fundamental change in their partner’s outlook and reassessment of their priorities following a ‘brush with mortality’ (Participant 9).

'He has just found that it has been a big shock, perhaps it was so easy that he wasn’t, he couldn’t have been here and he wouldn’t have been here to do that and now he is able to, he’s going to make the best of that time.' (Participant 10)

'He knows that his accident was kind of so serious that he might not have survived and he might not have been here, so I suppose he just appreciates the time that he has with her.' (Participant 8)
Although all participants described some degree of recovery, for the most part they were unable to pinpoint a time or describe a clear picture of the process of how this came about.

'She just somehow inside realised hang on I've got children to look after. I don't know to this day how she did it.' (Participant 4)

'Yeah, I would say it was yeah. I honestly could not put my finger on it and say, that's it, things started improving cos I couldn' put my finger on it.' (Participant 5)

Participants generally reported the recovery in parenting competence and involvement to occur as part of a wider recovery in function following the injury. Their descriptions of this wider recovery, however, also remained vague and again they were unable to describe this in any great detail. Although 'the recovery' was frequently mentioned by participants it remained an almost intangible experience. This seemed to be at least partly due to its gradual and piecemeal nature as participants seemed to be only vaguely aware of the improvements in their partner's functioning as they occurred. Many participants reported only becoming aware of these improvements in hindsight, when they compared one period to another.

'Maybe about, I don't know, I don't know if there was a time where, that I thought 'oh he's better,' it was a progression over a period of time and I know what you mean, its difficult to kind of comprehend.' (Participant 10)

'There was millions of stages in his recovery, and still now. Like people will say to me 'how is (husband)?' and I will go 'he is ehm pretty much back to normal,' right. And then I have to said that to people about 6 months ago, said, 'och he is pretty much back to normal.' And then 6 later months I look back and I think, Christ! He wasnae normal at all but he is normal now!' (Participant 7)

Theme 2: Loosening Control

As participants narratives focussed away from the period closest to the injury they began to discuss an increased confidence in their partner's abilities. As well as making reference to their increased skills and abilities participants expressed a renewed confidence in their partners as independent, capable parents.
'Now I mean now I don’t even question, away he goes and does these things [looking after the children] and I don’t, I don’t bother at all.' (Participant 6)

'Some of our peers who don’t really know, not really friends you know as well who don’t know much about, maybe don’t even know that he has got a brain injury, will be like ‘oh, how will he manage that? [managing the children when partner goes back to work]....That is not a question I have to ask.' (Participant 10)

The increase in confidence seemed to closely mirror the changes and improvements in their partner’s parenting.

'Probably as he improved ken? I dinnae worry, I dinnae worry really about things now.' (Participant 2)

This new found confidence in their partner’s abilities was accompanied by a loosening of the tight control they had previously exercised over their partner’s parenting. Participants described this handing back of parental responsibility and independence as a gradual and measured process where small responsibilities were increased over time as the non-injured parent judged their partner able.

'lt just happened gradually ehm I don’t think there was any sort of time when I said right I am not organising you any more, I think it just evolves.' (Participant 10)

It was clear from participants’ narratives that this was often a process of the non-injured parent handing back responsibility, rather than the injured parent taking this for themselves. Participants described themselves as judging their partner’s abilities and titrating responsibilities to suit their perceived abilities.

'So he had to do a lot of hard work in learning strategies to get him, you know, to learn how to read a map to route find, to do all these sort of things. So he’s had a lot of hard work to, do to remember all these things. I’ve tested him by giving him a shopping list, send him down the shop, see how long it took him, things like that. Once I knew he could cope down to the shop then yeah I’d let him take the kids down the shop, things like that.’ (Participant 1)

'So you’ve always got to, you are always very careful you don’t know which way it is going to go. Some days he could take the extra pressure, the extra amount of responsibility. Other days it doesn’t go in because, its as if his brain will store so much and then it shuts down.’ (Participant 6)
Consequently, the handover of parenting to the injured parent appears to occur on the non-injured parent’s terms, when they feel their partner is ready and has, on the surface, much in common with ‘pushing involvement.’ This process does, however differ from that outlined earlier, as the former process involved the injured partner being pushed into interactions which were closely monitored by the injured parent. There was hence little handover of actual responsibility and the pushing in itself seemed to undermine their status as independent parents. The present process, however, appears to represent a relaxation of control and moves the injured parent, albeit gradually, away from a position of being managed.

Participants differed in the amount of responsibility they had reallocated to their partners. All participants, for example, described leaving their partner in sole charge of their children for some length of period. The length of this period, however, varied from a couple of hours to whole weekends. For three participants in particular the level of responsibilities given to their partner remained quite low and appeared to be related to their perception of their partner’s ongoing difficulties. Other participants who described handing over a great deal of responsibility, however, also mentioned some areas where they had retained a certain level of their previous control.

'I mean it is definitely more shared now, but ultimate checking, but whether that would have been the case without the accident I don’t know.’ (Participant 8)

For participants, however, this handover appeared to reflect a return to, or at least a step towards, a position of greater equality within the management of parenting and within the marital relationship.

'Probably he would he would take himself away from the situation [daughter becoming upset] and I would [step in], but then there are situation where I get to that point and he takes over, so its. I suppose it is getting much more back to the way things were before his accident.’ (Participant 8)

'So no I would say it is pretty equal in a lot of respects. It has come a long way, we’ve managed to. The progress has been gradual but I am hoping that we have got it right that we now share responsibility and we take it equally, that we as times we both go ‘can you deal with it? Can you deal with it, while I do this.’ Or I’ll say ‘see to so and so while you do that.’ (Participant 7)
Theme 3: Children Adjusting with Improvements

In addition to injured parents becoming more involved with their children, participants also identified a reciprocal process where children became more relaxed with the injured parent. They described their children as approaching their parent more and beginning to place parental demands upon their parent once again.

'And em the kids must have noticed [he's better], they just seem to have relaxed that little bit now and they will go to him for things. (daughter) goes to (injured partner) for things more than she would come to me now.' (Participant 6)

'She will jump all over him, jump on his head, you know, get piggy backs and all that now. Whereas she wouldn't have done that after the accident.' (Participant 7)

Participants attributed this new found confidence in their injured parent to the children's awareness of the improvements in the parent's abilities.

'But I don't think they feel everything from dad has to be double checked or whatever. So they will quite happily accept his responsibility {laughs}. ......I think they probably kind of sussed for themselves ...... as (husband) was functioning better, it was a natural progression' (Participant 9).

'You know, he doesn't need more sleep, he doesn't, you know, he still does ...... have difficulty finding words sometimes. And he, well the seroxat totally overcame the anxiety problems. So as he got better, she just adjusted with him.' (Participant 7)

Consequently some improvements in the child’s relationship, particularly with regard to placing demands, appeared to be directly related to the improvements in the parent’s functioning and the children recognising and adjusting to these increased limits.
Subcategory 2: Accepting the Parent who is a Little Bit Different

A second subcategory to emerge from participants’ narratives concerned their children’s growing acceptance of the injured parent. As was emphasised earlier, not all injured parents attained the same level of recovery and even those who made great improvements continued to experience some difficulties. Consequently, as well as describing their children’s adjustment to the improvement in the injured parent, participants also described their children’s acceptance of the changes in the injured parent. This contrasts with the previous theme as this acceptance is not conditional on improvements in the parent, but seems more related to the areas they continue to experience difficulty.

Participants described their children as gradually adjusting to the changes in their parent and coming to accept or tolerate their parent’s new limits and sometimes their negative behaviour.

'[Husband’s story reading] is really boring; na na na na, its quite monotone and it doesn’t have intonation or anything and he would be like that you know. Goldilocks ...came ..... down.....stairs, and it would be very much like that and she would just be sitting there and you know, she would sometimes correct him and try to chivvy him up a bit. Oh she’s long suffering she never, she was never out and out ‘no I want mum to do it!’ (Participant 7)

'Yes, before they just thought that their mum was shouting at them all the time whereas now they realise its, although she is nae doing it so much, they just seem to shut themselves off from it, just get on with it basically, ‘aye okay’ and get on with it' (Participant 5).

Even those participants who had previously described something of a breakdown in parent child relationships also described some degree of acceptance and tolerance of the changed parent. Participants described this acceptance as growing as the children became used to the changes in their parent. Many descriptions of their children’s acceptance also conveyed a sense of this acceptance as being automatic and unquestioning.

'They just got used to that was how dad was and this is how dad is and that was it. ’ (Participant 6)
They know they've got a dad and okay, he's a little bit different but he's still their dad and they accept, kids accept things a lot better than adults do...... I mean dad's dad, you know it's who he is.' (Participant 1)

Participants often indicated that their children had been far more able to accept the changes in their parent than they themselves had been. Although participants also reported a growing acceptance of the changes in their partner, this appeared to be more hard won and reluctant than their descriptions of their children's acceptance.

'I think the kids have probably come to terms with the fact that their mother might not be what she was. They have maybe accepted that, dinnae get me wrong she might be, she might not be.' (Participant 5)

Participant five above, for example, states that his daughters have accepted the changes in their mother as permanent, yet he himself remains reluctant to acknowledge them as such. Participants, including the parents of the adolescents in the sample, attributed their children's relatively easy acceptance to their child's age and their lack of complete understanding of the changes in the parent. They also stated that their children were less able to compare the injured parent's new characteristics with their pre-morbid personality and capabilities as they had a relatively impoverished memory of the parent's pre-injury, characteristics. This lack of insight was perceived as aiding their children's acceptance and allowing them to adopt a far less critical view of the injured parent.

'But then the kids, they're nae gonna think they've lost out. Ken cos they're nae gonna ken, the likes I dae.' (Participant 2)

'They are just adapting, that's how it is. I Don't know even know if they kind of realise that everybody's dad doesn't go for a lie down, I don't even know if they realise that.' (Participant 9)
Results – Interpretative Analysis

The previous section outlined a descriptive analysis of the main categories to emerge from the data. Three main categories, which are proposed to constitute the core category and a fourth related category were described. The following section discusses possible relationships between these categories and their constituent subcategories in an attempt to build a provisional framework for understanding the changes in parenting perceived by the non-injured parent. This framework and the relationships proposed within it, however, remain tentative and are acknowledged as requiring further data collection to lend them more credibility.

The Core Category

The core category to emerge from the data was ‘becoming the superordinate parent.’ This core category represents the shift in both the injured and non-injured parents’ relative positions within the parenting dyad. The injured parent appears to begin to occupy the role of lead parent, who assumes responsibility for all other members of the household. The injured parent reciprocally begins to occupy a more junior status as a parent. Becoming the superordinate parent, therefore, is conceptualised as not only a shifting of responsibility but also as a shift in the family structure, as one parent assumes a role superordinate to the other.

This concept is placed at the centre of the tentative model derived from the data. A diagram of this is given in figure 3.2. For clarity, this has been built mainly at the level of sub-categories. More detailed diagrams of the individual main categories are given in Appendix two.
Overview of the Provisional Framework

-损失能力
-留恋
-接受额外的孩子
-疏远
-接受成为超权威父母
-接受拥有一个有点不同的人
-重新分配需求
-松动控制
-改善
-感到负担
-恢复能力和参与
-接受超权威父母的最终责任
-接受超权威父母的最终责任
-接受超权威父母的最终责任
-接受超权威父母的最终责任
-接受超权威父母的最终责任

图3.2 框架概述
Overview of the Framework

The first main category ‘loss of a capable parent’ described the non-injured parent’s perception that they and their children had lost the input and the support of a capable second parent. This loss appeared to mainly be composed of changes in two domains, a loss in parenting skills and a change in the extent of their partner’s engagement and emotional relatedness to the children. The injured parent’s difficulties and detachment, amongst other factors, also appeared to influence the non-injured parent’s appraisal of the injured parent as participants described beginning to view their partner as less of an equal partner and instead as a childlike or dependent figure. It seems possible that this loss in parental status occurs partly as a consequence of the injured partner ceasing to enact their former parental role. The change from a capable independent adult, to a dependent role, also constitutes another aspect of the loss perceived by participants and forms the third sub-category ‘having this extra child.’

These losses in themselves are an aspect of becoming the superordinate parent, as the perceived loss of a capable co-parent automatically places the non-injured parent in the position of being the lead parent. In addition, these changes appear to cause the non-injured parent to view their partner as unable to carry the same level of responsibility for the family and as being unable to manage their own parenting independently. This realisation, therefore, appears to cause a shift in the non-injured parent’s role as they absorb the responsibilities no longer met by their partner and take control of the family, shifting them more firmly into the superordinate role.

The non-injured parent’s perception of their partner as dependent and childlike may also influence this shift in a second way. As well as underlining their perception of their partner’s difficulties in assuming a parental role, this change in appraisal seems to mark the beginning of a shift in power within the parenting dyad. As described previously, becoming the superordinate parent also involves taking a managerial role over the injured partner. It is possible that their perception of their partner as dependent and childlike places the non-injured parent in a position where they feel able to begin to manage their partner’s
parenting. It is hypothesised that, if this shift did not occur and the non-injured parent continued to perceive their partner as an equal adult, they might not feel able to oversee and instruct them in the same way.

The second main category described the non-injured parent as ‘taking charge’ and assuming the role of superordinate parent within the family. This category is proposed to be comprised of two subcategories which represent the actions adopted by the non-injured parent in response to the changes in their partner, ‘taking charge of your partner’s parenting’ and ‘taking charge of the family.’ These actions define the non-injured parent’s position as the superordinate parent as they absorb responsibility for both the family and their partner’s parenting. ‘Taking charge of the family’ is conceptualised as an action, as it represents the non-injured parent’s active acknowledgement and acceptance of their responsibilities, rather than simply the heaping of these responsibilities upon them. ‘Taking charge of your partner’s parenting’ is also considered to be an important and defining aspect of becoming the superordinate parent as the non-injured parent’s overseeing of the injured parent’s parenting underlines the shift in roles and parental equality which constitute the core category.

Another theme which emerged in this category was ‘feeling the burden of ultimate responsibility,’ which is proposed to arise as a consequence of the non-injured parent’s transition to superordinate parent. This concerned both their perceived general burden and (for some parents) perceived costs to their own parenting.

A third main category, which contributes toward the assumption of a superordinate role, is the children’s selection of the non-injured parent as the lead parent. The children’s changing expectations of their parents and growing reliance on the non-injured parent locates the non-injured parent in the position of superordinate parent and reinforces their new position in the household. This selection may arise partly as
a result of the children's awareness of the changes in the non-injured parent. The children’s selection may also, however, have a reciprocal relationship to the non-injured parent's new role within the family and may exist as both an aspect of this role and consequence of the adoption of the superordinate role.

Some participants, for example, described their children as developing an awareness of the changes in family structure and it is possible that the children’s observations of the non-injured parent managing the parenting of their partner influences this perception. Participant six stated:

'I shouldn't be having to go to the kids and say 'just ignore him,' because they are not going to gain the respect back that way through me saying those things either.' (Participant 6)

Consequently, it is possible that the children’s observations of the non-injured parent’s role as lead parent and their management of the non-injured parent influence their perception of both parents. This may add to their perception of the injured parent as an unreliable source of support and make it more likely that they will treat the non-injured parent as their main source of support.

Participants’ narratives also discussed, to varying extents, the gradual relinquishment of the superordinate role and a transition to a more stable mode of functioning in the family. Participants were clear that some recovery of abilities and involvement had occurred, although their accounts of the source of this recovery remained vague. Depending on its extent, this recovery appeared to lead to both a gradual loosening of the parental control and a reallocation of the children's demands. Consequently, 'recovering abilities and involvement' is conceptualised as an intervening condition which determines the extent and duration of the assumption of the superordinate role.

'Acceptance' emerged as a separate category within in the data as acceptance did not appear to be dependent on the injured parent's recovery. This process appears to occur alongside the children's
adjustment to improvements in their parent and may, in fact, exist as an alternative process as a greater degree of acceptance may be required in families where parents experience less recovery. This appeared to be the case in participants’ current accounts as those participants who described the smallest amount of recovery also discussed acceptance to the greatest extent. For the majority of participants this process of acceptance also appeared to represent a move away from the position of superordinate parent. Children were described as approaching the injured parent more, accepting their limitations in parenting tasks and increasing their expectations and demands of the injured parent. Thus, ‘acceptance’ seems to refer to the children’s acceptance of the changed parent as a parental figure.

The fourth main category, therefore, seems to reflect a move towards increased stability in the family and an, often partial, relinquishment of the superordinate role. Although a similar process emerged from all participants’ narratives the speed and extent to which families moved toward this stage varied hugely. Some participants described reaching a stage of handing back all responsibility within a year post injury. In contrast, others described their partners as having only regained a relatively small portion of their parental role several years post injury and these participants seemed to continue to occupy a superordinate position within the family.
Discussion

Summary of the Research Question and Findings

The present study sought to investigate the impact of parental acquired brain injury on parenting and parent-child relationships by conducting semi-structured interviews with 10 participants whose partner had sustained a brain injury in the last six years. Data were collected and analysed in accordance with grounded theory procedures and a core category ‘becoming the superordinate parent’ emerged from the data. This core category described an alteration in both parent’ roles and positions within the household, wherein the injured parent ceases to enact their previous parental role and appears to shift toward a more junior parental status. Reciprocally the non-injured parent is hypothesised to assume more authority within the family and begin to occupy the role of lead parent. In doing so the non-injured parent seems to adopt responsibility for their partner and for their partner’s parenting. Participants also described a shift in their children’s perceived expectations towards placing less demands on the injured parent, which again seemed to situate the non-injured parent in the position of lead parent. For many families this seemed to be a temporary shift in roles as many injured parents regained aspects of their former role and began to parent more autonomously over time.

Discussion of the Findings in the Context of Previous Literature

The main findings of this research to relate to role change within the family. Family roles have been defined as ‘integrated and socially determined sets of beliefs, values and expectations that define how one ought to behave’ (Maitz & Sachs, 1995, pg 3). Other authors have previously discussed the impact of ABI on family members in terms of role change, although with some exceptions (e.g. Leatham et al, 1996) this concept has rarely been directly investigated.
It has been proposed, however, that ABI and its sequelae compromise the injured individual’s ability to enact their previous roles within in the family (Laroi, 2003; Leatham et al, 1996). Consequently, it is argued that in order for the family to continue to meet the needs of its members, the family system must adapt and redistribute these roles. Other family members may, therefore, assume the roles no longer fulfilled by the injured family member (Maitz, 1990).

This seems to have been the case in the current sample as participants reported assuming the roles and responsibilities previously occupied or shared with their partners. As family roles consist not only of actions, but also include expectations, the children’s changing expectations can also been viewed as a form of role change. Other researchers have reported similar findings. Gosling & Oddy (1999), for example, in a partly qualitative study found that wives of traumatically injured husbands reported assuming ‘total’ responsibility within their families. Similarly, Leathem et al (1996) found that spouses of traumatically brain injured males reported experiencing role changes in terms of increased household and family responsibilities and that this was associated with increased self-reported stress.

It is argued that such a redistribution of role occurs as a normal reaction to the disruption caused by a family member’s brain injury and some degree of role transition is required to maintain the family’s functioning and equilibrium (Maitz, 1990). It is also argued, however, that if this transition is extreme, sudden or unwanted this can lead to ‘role strain’ or ‘role overload.’ (Leaf, 1993; Laroi, 2003; Maitz, 1990). This may in turn cause feelings of stress or burden, as was, for example, found by Leathem et al (1996). This also seemed to be the case in the present sample as all participants reported some feelings of pressure and burden in relation to their new role within the family.

In addition, in line with previous predictions (e.g. Lezak, 1978), five participants also perceived the pressures of meeting the demands of their new roles to compromise the quality of their own parenting.
This perception was not, however, universal, as half of the participants interviewed reported no impact upon their own parenting. It is possible that this difference is attributable to the amount of role change experienced, as those reporting greater levels of change seemed more likely to report an impact on their own parenting. This hypothesis, however, requires further investigation to substantiate the present findings but may warrant further attention as previous research has indicated that changes in non-injured parent’s parenting may be particularly important in terms of child wellbeing in families affected by ABI (Pessar, 1993; Uysal, 1998; Visser-Meiley et al, 2005b).

In addition to reflecting the reallocation of parenting responsibilities, the core category ‘becoming the superordinate parent’ also captured a sense of the change in status within the parenting dyad. Participants seemed to cease to perceive themselves as having an equal relationship with their spouse, instead viewing the spouse as dependent and sometimes child-like. In addition, participants described exercising control over their partner’s parenting, indicating the assumption of a superordinate role within the parenting dyad. There appeared, therefore, to be a change in the family structure, wherein the parents no longer retained an equal status.

These findings echo previous research which has described a change in perceived equality within the family relationships of brain injured adults. Gosling and Oddy (1999), for example, found that non-injured spouses of traumatically injured adults reported a perceived loss of equality in their marital relationships and described feeling like a parent to their injured spouses. Similarly, in a qualitative study, by Howes et al (2005), traumatically brain injured women described experiencing a transition to childlike role within their marital relationships.

The present findings are also in line with clinical descriptions by authors such as Laroi (2003) and Maitz and Sachs (1995) who argue that the sometimes dramatic shifts in family roles found in families affected
by brain injury may cause a fundamental change in the family structure. The concept of family structure comes from structural family therapy approaches which assume that families are to some extent organised in a hierarchical fashion with some members, e.g. parents, occupying positions of greater power and authority than others e.g. children (Haley, 1987). Drawing on this concept, Maitz and Sachs (1995) propose that injured members who are unable to perform in their previous roles may lose their previous status within the family hierarchy and be relegated to a similar status as the children in the family.

Cleary such a transition may have a profound impact on the quality of the injured parent’s marital relationship (Gosling & Oddy, 1999). It has also been argued that the loss of a clear family structure and confusions regarding the position of the injured parent within this structure may create disequilibrium and stress the whole family system, leading to conflict and strain (Maitz and Sach’s, 1995). Maitz and Sachs illustrate this point with a clinical case example of a family where the children of a brain injured father variously taunted or ignored their father. In the present sample, some participants described a less extreme variation of this scenario, as three families described their children as ignoring and disputing the authority of their injured parent. It seems that such behaviour may be partly created, therefore, by a loss of clear family structure and boundaries between the parental and child subsystems.

Maitz and Sachs (1995) argue that such families may require therapeutic intervention to achieve a more equal distribution of power and roles in order to regain stability. For the most part, however, participants in the present sample described a gradual return to a more stable family structure over time. Although several participants did not describe a complete return to a position of equality, most participants described some degree of reenrolment by their partner and a loosening of control by themselves. In some cases this may be due to the relatively good recovery described by some participants.
Kay & Cavallo (1990), however, also argue that family system may initially undergo a period of crisis in response to a brain injury, which if maintained over a lengthy period may lead to family dysfunction. They argue, however, that many families will gradually evolve a new way of functioning which maintains equilibrium and meets the needs of all family members. When looked at from this perspective it is possible that the re-organisation of family roles represents a normal stage of adaptation to an abnormal set of family circumstances which families may eventually progress through.

The present study also described several more specific changes in parenting and parent-child relationships which have been anticipated or described in the previous literature in this area. Participant’s described observing various changes in their partner’s parenting, particularly in terms of a deterioration of previous parenting abilities, emotional detachment and increased irritability in their parenting. These finding are generally in line with previous clinical descriptions and research findings (Ducharme, et al 2002; Lezak, 1978; 1988; Pessar et al, 1993; Urbach 1991; Uysal et al, 1998).

For example, one of the most striking features of participants’ accounts was their perception of their partners’ emotional detachment. Other researchers have reported similar findings. Pessar et al (1993), for example, reported a decreasing level of positive parenting behaviours such as showing interest in the children. Similarly, Uysal et al (1998) reported that injured parents in their sample reported less nurturing and less active involvement with their children. Such findings are also in line with the wider ABI literature which describes social or emotional withdrawal as some of the most common and distressing sequelae of ABI for family members (Ergh et al, 2002; Gosling & Oddy, 1999).

Such findings may have implications in terms of their impact on child development. Pessar et al (1993), for example, found that reduced involvement and less positive parenting behaviours, such as showing an interest in their children, were associated with increased child emotional and relationship difficulties.
Similarly, in a review of the literature on parental chronic illness and child psychosocial functioning, Amistead et al (1995) argue that decreased parental attention and withdrawal may exert a detrimental influence on child development. Thus, although an investigation of the impact on child wellbeing is beyond the scope of the present study, the impact of the brain injured parent's emotional withdrawal seems to warrant further investigation.

In common with Uysal et al's (1998) results the present study also found that parents who had sustained ABI were perceived as having reduced capacity to perform parenting tasks, particularly more cognitively demanding activities, such as planning and organising. Some participants’ accounts also indicated that a decrease in parental abilities and skills may lead to decreased frustration tolerance and increased irritability with their children, echoing concerns raised by Ducharme et al (2002). This hypothesis, however, remains tentative and requires further investigation.

Several differences are also apparent between the previous literature and the findings of the present study. Firstly, although participants described their partners as experiencing difficulties with increased irritability, no participant disclosed physical abuse against their children. This differs from the results of Butera-Prinzi and Perlez's (2004) study which suggested children of brain injured parents may be at high risk for physical abuse. Such a discrepancy may be attributable to the fact that Butera-Prinzi & Perlez (2004) used a sample drawn from a family intervention service and the present study utilised a sample from a general clinical neuropsychology service. It is, however, possible that physical violence towards the children had occurred within these families but that participants were unwilling to disclose such a sensitive matter in a one-off interview.

In addition, the present study did not find the marked level of parent-child relationship breakdown described in the clinical literature. Again this may be due to participant's willingness to disclose such
sensitive matters. For the most part participants described their children as being cautious and hesitant around the injured parent. Four participants did, however, describe a more extreme reaction in their children, principally marked, as predicted by Lezak (1978; 1988) by avoidance of the injured parent.

It seems that such reactions were more common amongst the slightly older children in the sample and this concurs with Pessar et al’s (1993) findings that teenagers experienced more relationship problems with their injured parents. Although the present findings require further investigation with a larger sample, it is possible that these increased difficulties are related to the older children and adolescent’s greater recognition of the changes in their parent. Alternatively, it has been suggested that some level of parent child conflict is a relatively normal, although not universal feature of adolescence (Carr, 1999) and it is possible that the relationship problems described by the parents of adolescents in the sample are a reflection or magnification of this.

Participants also described some improvement in their children’s relationship with the injured parent over time as they described their children’s growing acceptance of the changes in the parent. Several authors have suggested that family members’ reaction to ABI progress through various stages such as grief and denial before arriving at an acceptance of the changes in the injured member (e.g. Lezak, 1986). The parents in the current sample described their children’s journey to acceptance as much swifter and easier than their own. This view of their children’s relative ease in accepting the changes in their parent contrasts with Butera-Prinzi and Perlesz’s (2004) findings as they found that four years post injury the children in their sample continued to report feelings of sadness, anger and grief for the loss of their ‘real fathers.’ This discrepancy may be due to the fact that many of the injured parents in the present sample went on to make a substantial recovery. It is also possible that the participants in this sample are mistaken in their perceptions of their children’s acceptance and are ascribing to a ‘myth’ that children are more able to adjust to traumatic events and losses than adults (Butera-Prinzi & Perlesz, 2004).
Clinical Utility

The findings of the present study indicate that parental acquired brain injury impacts on the entire family system and may affect the wellbeing and relationships of both spouses and children. It indicates, for example, that child-parent relationships may become disrupted for a period post injury, both in terms of the parent’s emotional detachment and irritability and in terms of the child’s response to the injured parent. Partners also reported experiencing increased levels of burden which may have a negative impact on their wellbeing and parenting. Many participants also stated that they felt, to some extent neglected by mainstream services, which they saw as geared to meet the needs of the injured member, rather than the wider family.

Laroi (2003) states that support for families affected by brain injury may take the form of general information and support or, in some cases, family therapy. Some families affected by parental injury may, therefore, benefit from general support and information, particularly during the earlier stages of adjustment to the injury. Such support may take the form of supportive counselling, provision of additional information, which may help normalise their families’ experiences or practical interventions aimed at lessening the demands placed on the non-injured parent. Some children may also benefit from supportive interventions, which perhaps could provide information in a developmentally appropriate form about the changes they are witnessing in their parents and allow them space to express and explore their feelings regarding these.

The present study that indicates that parental brain injury may produce role change and family disequilibrium for a period post injury. It seems possible, however, that these changes occur as a normal reaction to the extreme circumstances these families find themselves in and many families manage to evolve beyond this stage. Care must, therefore, be taken not to pathologize this stage in the family’s adjustment. It seems, however, that some families may experience more difficulties negotiating the changes in family structure than others. It is, therefore, hypothesised that some families, for example
where the non-injured parent experiences ongoing feelings of burden or where marked child parent conflict or relationship breakdown is apparent, may benefit from a more intensive form of intervention such as family therapy. Such an intervention could perhaps be aimed at finding and establishing a family structure and distribution of roles which are acceptable to and meet the needs of all family members.

**Methodological Issues**

**Design**

The use of a single informant is a key methodological limitation in the current study. At the outset of the study it was decided to interview only one family member with the aim of saturating a single viewpoint. The decision to select the non-injured parent was supported by later comments from some participants who stated that their partners would not have wished to be interviewed, due to lack of interest or because they found discussing their injury and its consequences too upsetting. A constructivist approach, however, highlights the importance of context and that different individuals may have very different perspectives of the same phenomenon (Willig, 2000). Consequently the current data gathered reflects the non-injured parents’ interpretations of their partners and children’s behaviour and it would be both interesting and informative to have interviewed injured parents and children in order to gain their perspectives on the changes in the family. In the absence of this, it is acknowledged that the conclusions reached by the present study remain tentative and viewpoint dependent.

In addition, the present study revealed that injured parents may become to some extent sidelined within their families. The choice of the non-injured parent as informant may, therefore, be viewed by some as being complicit in this disempowerment. Although this is acknowledged as a shortcoming of the present study, it is also emphasised that most of the research carried out on the impact of brain injury on the family has also mainly sought the views of non-injured family members for similar methodological reasons (Howes et al, 2005).
In addition, although the quality of the present study is enhanced by the use of two additional raters for a sub-set of transcripts, a member check was not carried out. It is hoped, however, that a member check can be carried out at a later date to enhance the credibility of the research.

Sampling

A key methodological limitation in the present research is its failure to reach theoretical saturation. Saturation is said to occur when no new information about a category or its properties emerges from further interviews and analysis (Strauss & Corbin, 1998). Several factors may have contributed to the failure to reach saturation in the present study.

Firstly, data collection was necessarily truncated by the availability of participants and by the time constraints involved in the project. Although all individuals meeting inclusion criteria in two neighbouring health boards, were contacted this produced a relatively small sample size of 10. The difficulty of reaching true saturation with a small number of participants was compounded by the variability within the present sample. The acquired brain injury population is extremely heterogeneous in terms of injury type, extent and type of sequelae experienced, and extent of recovery. As can be seen in appendix one, this level of variability was also present in the sample as it included four different types of injury, post injury intervals of between two and six years and substantial variation in terms of assessed recovery status.

In addition, the sample also varied a good deal in terms of family composition, age and number of children. Children’s ages at the time of their parent’s injury varied between 3 weeks and 13 years. The developmental and parenting tasks faced by these families are, therefore, likely to be hugely divergent. The sample drawn, consequently, represented a wide variety of possible experiences and it may be unrealistic to expect to saturate all categories and their properties with a relatively modest sample size. Ideally, if more participants had been available, it would perhaps have been preferable to have drawn
participants from a more homogenous group in terms of family composition and injury severity or recovery and saturate this sample, before going on to theoretically sample other types of families to substantiate and expand the resultant theory.

Due to the shortage of available participants, however, true theoretical sampling was not possible, further reducing the potential to reach saturation. Although the questions asked in interviews were geared toward developing the emergent categories, this has been described as an abbreviated version of grounded theory which is less likely to produce saturation (Willig, 2001). Some areas of variation which emerged from the data could perhaps have been further elucidated by theoretical sampling. As noted earlier, the two parents of adolescents interviewed described greater parent child relationship difficulties and it would have been advantageous to recruit more parents of adolescents to further investigate this.

Perhaps more importantly, the sample included only two male informants. Even in today’s society differing parental roles are typically adopted and assigned to mothers and fathers. Women are more likely to carry the burden of childcare and parenting cannot be considered a gender neutral activity (Dallos & Draper, 2000). Consequently one might expect a theory looking at the changes in parenting to require modification depending on the gender of the injured parent. Certainly, some differences emerged from the two accounts by male participants. They both described a greater degree of role transition and greater burden in terms of doing more practical childcare tasks. Conversely, they reported feeling less burden for other responsibilities such as decision making, than female participants. It is therefore possible that the role transitions which are greatest carry the most burden and that these differed between men and women in the sample. This hypothesis, however, requires further investigation due to the lack of male participants in the current sample.

The lack of male informants in the present study is, however, a relatively common characteristic in this research area, which has generally focused on the female relatives of male brain injury survivors.
(Gervasio & Kreutzer, 1997, Kay & Cavallo, 1991). Such a bias is, however, generally attributable to the fact that brain injury is roughly twice as common in men as women (Richardson, 1990).

Although the variability in the sample presents several methodological problems and limitations this variation, in some senses may also represent a relative strength of the study. During analysis several principal categories arose which appeared to be common to and represent the experiences all the participants involved. This ability to encompass the experiences of a range of individuals with different demographic and injury related characteristics may, therefore, represent a strength in the current study.

Transferability

It has been argued that the term transferability is more appropriate to qualitative research than the usual criterion of external validity (Lincoln & Guba, 1985). Lincoln and Guba (1985) argue that qualitative researcher’s priority is to produce credible research which represents the individual perspectives of participants and provide sufficient contextual information regarding these participants. This then allows readers to judge if the findings of the research are likely to be transferable to their clients or participants. Some key characteristics of the present sample which may influence the transferability of results are, therefore, highlighted.

The present sample was recruited from the clients of Clinical Neuropsychology services and hence may represent a group with more cognitive difficulties than would be found amongst the wider brain injury population. In addition, the sample comprised some apparently very stable families. Participants appeared to be drawn from mainly slightly older couples who had been married for several years, the majority of whom stayed together post-injury. Such a sample may not be typical of the wider (particularly traumatically) brain injured population who are usually younger, described as leading less stable lifestyles (Kreutzer et al, 1994a) and experience high rates of post-injury separation (Wood & Yurdakul, 1999). It is, therefore, possible that the present sample represents a sample of particularly well adjusted families.
Although the opt-in rate was reasonably high at nearly 50%, it is unclear whether the opt-in process produced selection bias in the sample, as it is possible that families who continued to experience more pronounced difficulties chose not to opt in. It is also, however, equally possible that the families who did not opt in chose not to as they had not observed an impact of brain injury on parenting and, therefore, did not see the study as relevant to them.

Future Research Directions

The findings of the present study could be built on by eliciting the perspectives of different family members. As stated above, further research is required to explore the experiences of families of female brain injury survivors and families with adolescents. In addition, many participant’s narratives in the present study focused on a retrospective account of an earlier period in their partner’s recovery. It may, therefore, be advantageous to recruit participants relatively early in the post-injury period in order to gain their contemporary perspective of this period. Moreover, the present study included only two parent families and future research on the impact of parental ABI on single parent families is also required.

Researcher’s Position and Reflections

The present study acknowledges that meanings are interpretive and are negotiated in the context of the researcher’s prior assumptions and experiences. Consequently, the researcher’s position is put forth in the following section. As this section deals with personal reflections it is written in the first person.

Whilst planning and conducting this study I was employed as a trainee clinical psychologist within child and family mental health services. The idea for the present study was sparked by a colleague’s remark that there was a paucity of literature in this area. My role as a trainee psychologist brings me into contact with children and parents whose family system is under stress and has led me to be interested in the way families can adapt and reorganise themselves in an adaptive or maladaptive manner in response to
difficulties. I consequently, became interested in the way a brain injury, which seemed to me to be a major event for the family, would affect the relationships within in families and the ways in which families would manage this.

During the research process a reflexive journal was kept with the aim of helping me become of how my own beliefs and biases may have influenced data collection and analysis. Early entries in the diary convey a sense of anxiety regarding the project. After committing to the project I was concerned about the content of the narratives I might encounter. Having read some earlier articles which outlined the devastating effects of brain injury I grew anxious that participants’ accounts would be extremely distressing. In the event, interviews were enjoyable and participants’ accounts seemed as concerned with coping as their previous losses. I grew to wonder, however, if my expectations and my role within child and family mental health services caused me to take an overly problem focussed perspective and follow up more on negative events in the narrative. I, therefore, tried to be aware of this potential bias in future interviews and maintain a more neutral position.

A second anxiety reflected in the diary, related to a worry about having ‘good enough’ data, as I was very aware that once collected this was what I had to work with. Examination of the diary indicates that I oscillated between being concerned that participants’ accounts were so complex that their analysis felt overwhelming and, at other times, that some narratives didn’t seem quite focussed on ‘parenting.’ I realised relatively early in data collection that my professional background may have been contributing to the latter concern. I came to realise that, as a mental health professional and a non-parent, I have a particular conceptualisation of parenting, as a predominantly emotional activity. Although participants discussed such matters, at the same time, many often took a far more practical view of parenting and discussed parenting as the process of ensuring their children were supervised and physically cared for. Reconsidering this definition, and incorporating it into my own, made sections of the narratives appear more relevant, rich and understandable.
Concluding Statement

The current study examined changes in parenting and parent child relationships within families affected by parental acquired brain injury. Analysis of data gathered from 10 non-injured parents indicated that ABI caused a shift in parental roles. Injured parents were described as being unable to enact their former parental role and non-injured parents appeared to adopt the roles and expectations no longer filled by their partner. Participants also described a second process wherein they began to move away from the position of lead parent. This involved both a gradual handing back of responsibilities to the injured parent and an acceptance of the injured parent by their children. This extent and rate of this second transition, however, varied widely between accounts. The findings indicate that acquired brain injury exerts a substantial impact on the parenting of both the injured and non-injured parents and professionals should consider the needs of the wider family when developing services for this population.
References


Note on Appendices

To preserve participants' anonymity appendices have been bound separately and can be accessed via special collections at the University of Edinburgh Library.