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### Parents' perceptions of accidental burns to their children : a qualitative investigation of the effects on parental well-being

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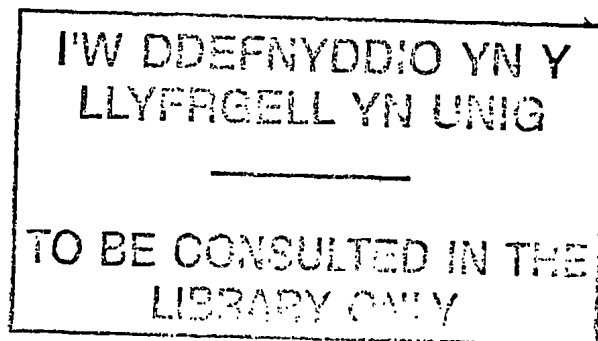
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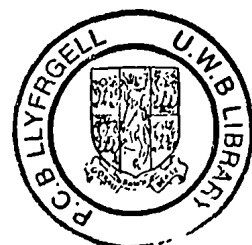
LANCASHIRE CLINICAL PSYCHOLOGY COURSE  
(Affiliated to the University of Wales, Bangor)

**Parents' perceptions of accidental burns to their children:  
a qualitative investigation of the effects on parental  
well-being**



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**Submitted in accordance with the requirements for the  
Doctorate of Clinical Psychology, 2000**



## Abstract

Despite the importance of family support for the recovery of children with thermal injuries, there has been little investigation into the needs and psychological well-being of parents during this time. The overall aims of this research were to investigate how parents understand the experience of having a child who has had a burn, to evaluate the relevance of existing models of parental adjustment from the paediatric health psychology literature and draw out implications for clinical practice. Ten families participated, including six with children who had over ten percent total body surface area burns. A qualitative research method was used and semi-structured interviews were conducted with individual parents and couples at participants' homes. Interpretative Phenomenological Analysis was used to analyse the data provided by the resulting interview transcripts.

The impact on parental well-being was explored through considering parents' constructions of their child's accident/injury and the consequences of the whole experience. Intra-personal, inter-personal and other threats were identified for parental well-being. Strategies for managing threats were also identified. Key threats to parental well being were related to the beliefs they held about the severity and seriousness of their child's injury, perceptions that the injury had had a negative impact on their child, blaming themselves for the accident and feeling blamed by others. Coping strategies included those which enabled parents to distance themselves from the emotions generated by the accident and its consequences, strategies which maintained parents' hopes about the future and their child's recovery and strategies that enabled threats to be managed by both parents or the whole family. The relationship between threats and coping strategies appeared to be complex and changed over time.

The results were compared with two bodies of literature which have emerged from research evaluating parental adjustment to chronic illnesses and traumas suffered by their children. Stress-resiliency models have focused research on a variety of stressors and protective factors that are proposed as influencing parents' generalised experiences of stress and trauma models, which conceptualise parents' adjustment as related to specific anxieties linked to their child's response to an illness or traumatic event or the parents' own experience of their child's health being threatened. Implications for future research and clinical practice were then considered.

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**Parents' perceptions of accidental burns to their children: a qualitative investigation of the effects on parental well-being**

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## Introduction

Over the last three decades there has been a growing interest in the psychological adjustment of children diagnosed with a chronic illness and their families. An interest has also developed in changes in family systems when health problems develop in children. A significant amount of this research has focused on the implications of chronic childhood disease for the development of psychopathology in children and/or their mothers. In general, researchers have concluded that although chronic childhood health problems increase the vulnerability of children and their parents to experiencing psychological problems, there is considerable variation in adjustment over time. Protective factors associated with these different outcomes have been sought (Wallander & Varni, 1998).

The current research study focuses on the experiences of parents whose children have been accidentally burned. The families approached to take part in this research had children who had been admitted to a regional paediatric burns unit. The unit recorded 224 children of five or under with a primary diagnosis of a thermal injury as having been registered with them for treatment from the beginning of 1998 to the end of 1999. Nationally, children of five and under make up the vast majority of the population admitted for these kinds of injuries (Wilkinson, 1998). Parents and families are therefore likely to be considerably involved with their hospital treatment and after-care. The ongoing treatment and rehabilitation required following an injury of this type may impact upon family life in a variety of ways, often for many years following the initial incident (Tarnowski, 1994). Parents, children and other family members are at risk of being exposed to both acute and chronic stressors resulting either directly from the injury and treatment required or from the impact these events have on the wider family system. Characteristics of families who cope well with stress and trauma and those who do not, have been identified in studies of other populations through clinical observations (Figley, 1989). However, research investigating the relevance of these characteristics in this population has been associated with the adjustment of the burns patients not their families.

To date, research in the area of paediatric thermal injury has largely focused on the adjustment of the child or patient rather than on the family, although the influence of parents on their child's adjustment has been considered (Blakeney, Herndon, Desai, Beard, & Wales-Seales, 1988; Blakeney, Portman & Rutan, 1990). The limited research suggests that the mental health or well-being of a small proportion of parents may be affected during the first two years post injury (e.g.

Cella, Perry, Kulchyky & Goodwin, 1988; Tarnowski & Rasnake, 1994). Although the evidence for causal links between child and parental adjustment in the area of paediatric thermal injury is contradictory (Meyer, Blakeney, Moore, Murphy, Robson & Herndon, 1994; Tarnowski & Rasnake, 1994) and direction of causality has not been established, it seems likely that parental well-being has implications for their ability to cope and provide optimum support and should therefore be considered along with the needs of the child (Le Doux, Meyer, Blakeney & Herndon, 1998). There have been no attempts in the literature to systematically consider mediators of parental adjustment, nor have models which have been suggested for related areas such as chronic illness been evaluated in relation to the experiences of parents of children who have been burned.

The current study highlights the experiences of individual parents and couples in relation to their perceptions of their mental health and influences on the maintenance of their well-being. In doing so, the research will offer a description of how parents currently understand and have come to understand the experience of having a child who has had a thermal injury and suggest which cognitive processes or beliefs, stressors or coping strategies appear to facilitate or hinder perceived parental adjustment. The descriptions will then be compared with existing models.

This introduction briefly looks at the consequences of thermal injuries for children and their families and then focuses on the limited literature pertaining to parental adjustment to their child's thermal injuries. It then outlines models which have been developed in response to empirical findings in other areas of paediatric health research and hypotheses arising from investigations into the impact of trauma on families. Finally, a critique of the existing literature and rationale for using a qualitative methodology is proposed.

## **Consequences of thermal injuries for children and their families**

### *Medical consequences*

Due to the rapid fluid loss experienced following a burn injury, children with burns over ten percent of total body surface area (TBSA) require immediate fluid resuscitation and those whose burns are over 30 percent TBSA are considered to be life threatening (Carvajal, 1980). With advances in surgical techniques and treatment, there has been a significant increase in the number of children surviving even severe thermal injury. Following hospital admission, parents

and children may be involved in a number of stressful medical procedures. Children may require intravenous fluid resuscitation, have to go through the painful process of wound debridement when their skin is “scrubbed” and dressing changes which may also hurt the child. After discharge, daily massage and hydration of scarred skin and the wearing of compression garments in order to aid scar formation may also be needed, as well as physiotherapy. Ultimately, skin grafts and surgical reconstruction may be necessary.

#### *Family involvement in medical treatment and rehabilitation*

The involvement of parents in their child’s medical treatment is likely at minimum to require them to massage their child’s scar for up to two years following the accident. Appointments to assess scar progress or the need for further interventions may involve parents in frequent trips to hospital. Whilst their child is under hospital care, parents may be given the option to hold or be with their child during painful or frightening procedures.

Studies have evaluated whether having parents present during painful or frightening treatment procedures helps children (e.g. Doctor, 1994). Although parents express a preference for being involved in their child’s care, the evidence for involving parents in the hospital care of a burn injured child is not supported by a reduction in the child’s behavioural distress (Foertsch, Hara, Stoddard & Kealey, 1996). Doctor (1992) suggested that involvement of parents could increase their sense of competence. However, the impact on parents and relatives of being present during these procedures has not been assessed.

#### *Psychosocial consequences*

The psychosocial consequences in the short to medium term for children who are burnt have been noted as anxiety and depression, post traumatic stress, increased behaviour problems and reductions in social competence (Armstrong, Gay & Levy, 1994). Family reactions such as indecision, intensification of pre-existing problems, denial, guilt, anxiety, helplessness, depression and anger have also been reported (e.g. Tucker, 1986). Other short term impacts on family functioning may include loss of income and disruption of normal family functioning when parents have to leave their other children with relatives for extended periods when they may be distressed themselves. Kaslow, Koon-Scott & Dingle (1994), note that although these reactions in children and parents are normal, they may become problematic if they persist and “interfere with optimum recovery if the patient, family and social system lacks adequate coping strategies

and resources” (Kaslow et al., 1994, p.196). Evidence for the persistence of behavioural problems in children in the long term is contradictory. In studies that followed up children for periods between one and 13 years, it appears that the majority does not exhibit severe psychopathology (Blakeney, Meyer, Robert, Desai, Wolf and Herndon, 1998; Tarnowski & Rasnake, 1994). Similarly, most parents do not evidence long term distress as measured using standardised assessments for anxiety and depression (Cella et al., 1988; Le Doux et al., 1998). A number of factors have been proposed as facilitating the adjustment of children who have been injured. Determinants of resilience for parents and siblings of burn injured children have received little attention.

#### *Family role in psychosocial rehabilitation*

Social support from the family has been found to be key in facilitating coping in the child and aiding psychosocial recovery (Tarnowski & Rasnake, 1994). Positive outcomes for paediatric burns patients have been associated with factors such as high levels of family cohesion and negative outcomes with factors such as low socio-economic status (Blakeney et al., 1990; Le Doux et al., 1998; Tarnowski, Rasnake, Gavaghan-Jones & Smith, 1991). Interestingly, in the Le Doux et al. study, families of children who had adjusted well, scored more highly on family cohesion measures than the reference population. This suggests that for these families, the burn may have facilitated the family in drawing more closely together.

Despite the importance of family support for the recovery of both adult and child burns patients, there has been little investigation of the needs of family members during this time, how they may be affected and how they adjust (Watkins, Cook, Randolph, Still, Luterman & Purvis 1996). Hypotheses relating to parental adjustment from this research are discussed in the next section.

#### **Parental adjustment to paediatric thermal injury**

Overall psychological difficulties for parents, if in evidence, have been found to diminish with time since injury. Factors common to parents who do well are unclear but child behaviour following the injury and injury severity have been proposed as influences on parental adjustment (eg. Meyer et al., 1994). Research exploring influences on adjustment is summarised in this section.

Earlier research suggested high rates of maladjustment in parents (e.g. Wright and Fulwiler, 1974) but many of these studies relied on clinical observations of small samples. Although a number of different standardised measures has been used in the more recent research, they vary from study to study making comparisons difficult. Some of the limited research using standardised measures such as the Parenting Stress Index (Abidin, 1986), has found that parents experience some psychological problems such as stress and depression (Blakeney, Moore, Broelmeling, Hunt, Herndon & Robson, 1993; Blakeney et al., 1998; Browne, Byrne, Brown, Pennock, Streiner, Roberts, Eyles, Truscott & Dabbs, 1985; Meyer et al., 1994). However, a recent cross-sectional study of parents of children of different ages who ranged from one to five years post burn, did not find that parents scored above the Beck Depression Inventory (BDI) cut-off score for depression (Le Doux et al., 1998). These authors suggested the BDI may not be sensitive enough to detect chronic unhappiness symptoms and is more proficient at detecting major depression. Similarly, a study using both quantitative and qualitative methods found that although maternal psychiatric morbidity scores on the General Health Questionnaire (Goldberg, 1978) were above the cut-off for the majority when their child was first admitted to hospital, this score had dropped to near that which would be expected for a random community sample of women within a week (Mason, 1993). Nonetheless, qualitative assessments associated with this study considered the majority of mothers to be suffering “continuing emotional trauma” when they were interviewed six months later.

The quantitative literature available suggests that parental well-being does not correlate with the severity of the child’s thermal injury (Blakeney, Moore, Broelmeling, Hunt, Herndon & Robson, 1993; Meyer et al., 1994). Although a qualitative study by Mason and Hillier (1993), which only included children whose injuries were severe enough to require skin grafts, concluded that a more severe burn injury to their child was associated with mothers being more likely to be still experiencing “emotional trauma” when followed up. Meyer et al. (1994) suggest that how parents view the burn is more important than the severity of the burn.

A study by Blakeney, Meyer, Moore, Murphy, Broemeling, Robson and Herndon (1993), found parents to have levels of stress significantly greater than the reference population used for the Parenting Stress Index. These parents tended to attribute their stress to characteristics of their children. Descriptions by parents of these children included, “demanding, moody and disappointing”, despite the fact that these children were rated by their parents and teachers as not

differing from reference groups of “normal” children on standardised behavioural assessment measures. Research by Meyer et al. (1994) using the same measures, found a correlation between high parental stress and poor child adjustment measures but also found that parents were stressed in areas unrelated to their children. Le Doux et al. (1998) found no difference between the BDI scores when parents of well and poorly adjusted children were compared, but did find reduced scores of family cohesion for the poorly adjusted group. The question still remains as to whether parental difficulties are caused by their child’s behaviour problems or vice versa.

In contrast, other researchers have suggested that the response of families to a burn injury may also be characterised by a post traumatic stress model of response to trauma. Cella et al. (1988) suggested that parents were more likely to respond with anxiety and stress responses specific to the trauma itself rather than more general factors assessed by measures such as the Parenting Stress Index. Studies which have used measures of post traumatic stress disorder (PTSD) have found parents to report varying levels of PTSD symptoms (Cella et al., 1988; Fukunishi, 1998; Le Doux et al., 1998; Rizzone, Stoddard, Murphy & Kruger, 1994). Cella et al. (1988) found significant levels of intrusive thoughts and images and avoidance responses in 25 percent of parents six to eight months after the accident, but found no evidence of elevated scores on standardised anxiety and depression measures. Interestingly, this study found that those who were rated as guilt ridden after the accident were more likely to be in this group although the nature of this guilt was not further explored. A retrospective study by Rizzone et al. (1994), found evidence of PTSD symptoms sufficient to meet diagnostic criteria in 16 percent of parents at the time of the interview but indicated 56 percent were experiencing some symptoms at that time. All of the studies used small, non-homogeneous samples and failed to investigate appraisals of the threat of the burn event or attributions of blame (Ehlers and Steil, 1995; Janoff-Bulman, 1985). Burn size was found to be predictive of PTSD symptoms by Rizzone et al. 1994 but not in any other studies.

Implications for parental resilience to the stresses associated with paediatric thermal injuries have not been examined up to now. It seems important to evaluate how parents’ psychosocial status changes from impaired to non-impaired and vice versa following the injury event. There is some suggestion from clinical observations that parents are most vulnerable following their child’s discharge from hospital and towards the beginning and end of their involvement with their children’s rehabilitation (Kaslow et al., 1994). The longitudinal research has found

conflicting results. Focusing on a group of parents whose children had been hospitalised for varying lengths of time, Meyer et al., (1994) found psychological distress and parenting stress to peak one year post-burn injury. However, Blakeney, Meyer, Moore, Murphy, Broemeling, Robson & Herndon, (1993) found depression highest two years after the initial injury but that after four years, parents' levels of depression were actually less than that of a comparison population. This group of researchers hypothesised that parents develop defensive coping strategies to minimise their depressive feelings and suggest that this may mean that they have difficulties in other areas or that their child will learn to deny their own feelings.

More recent research focusing on the responses of parents of more severely burned children (above 80 percent of total body surface area), has found that distress levels according to the Parenting Stress Index neither improved or remitted over the 13 year follow up period (Blakeney et al., 1998). Cella et al. (1988), found anxiety and depression symptoms to remit six to eight months post-burn but PTSD symptoms, especially those related to avoidance responses, to remain the same for a percentage of parents. Indicators of those issues which parents are more predominantly troubled by at different points in time have yet to be systematically discerned.

The extent to which parental well-being continues to be affected by their child's injury and the influence this has on their ability to support their child or manage their behaviour is unclear. Further, whether any difficulties found can be characterised as generalised stress or as specific stress responses to the injury event itself or experience of having a seriously ill child, are also unclear. The existing literature suggests that there may be a number of factors that are protective of parental well-being but it has not sought to identify them. As noted by Tarnowski & Brown (1994), the burns research has been hindered by the lack of a theoretical framework on which to base multi-variate studies.

The next section describes models which have been developed in response to empirical research and clinical observations of parental and family adjustment to other paediatric health problems which may facilitate exploration of factors that hinder or aid parental adjustment to their child's thermal injury.



## **Models of parental and family adjustment to paediatric health problems**

Whilst some researchers argue that the influences on adjustment in children and their parents are common to different childhood chronic disorders (e.g. Wallander & Varni, 1998), others suggest that there are significant differences in the way in which families and children adjust depending on the child's condition (Kazak & Nachman, 1991). As this issue has not yet been conclusively addressed, it seems important to evaluate the relevance of existing models to the experiences described by families whose children have suffered different health crises, including thermal injuries.

It could be hypothesised that the experiences of parents whose child has been accidentally burned, may initially resemble those of parents whose children have unexpectedly been diagnosed with a chronic health problem that requires continual readjustment. An alternative hypothesis could be, that as children with thermal injuries may make a full physical recovery with little scarring, parents' experiences may be more like those families who experience an acute trauma or crisis. There are a number of models that are currently proposed in the paediatric chronic illness and trauma literature. However, the combination of factors such as: the sudden onset of health problems associated with a thermal injury; the possibility of death due to fluid loss from the injured area; the high risk of infections developing; the participation of parents in painful medical procedures involving their child and the extended period of after-care sometimes required to aid scarring, means that a conceptual model of parental adjustment to their child's thermal injury may be more specific.

A number of conceptual models have been developed in relation to families where a child has a disability, cancer or a chronic illness with onset in childhood. The model that has been most widely adopted and empirically tested is the disability-stress-coping-model introduced by Wallander, Varni, Babini, Banis, DeHaan & Wilcox (1989). A more linear model, the transactional stress and coping model (Thompson, Gil, Gustafson, George, Keith, Spock & Kinney, 1994), also takes into consideration maternal adjustment and was developed in relation to children who have cystic fibrosis.

More recently other researchers have suggested that parents' reactions may be characterised by models of adaptation to trauma similar to those proposed for post traumatic stress disorder (e.g.

Barakat, Kazak, Meadows, Casey, Meeske & Stuber, 1997; Barnes, 1995; Figley, 1998; Landolt, Boehler, Schwager, Schallberger, & Nuessli, 1998).

Other researchers and clinicians have discussed the influence of cognitive processes and belief systems on parents' adaptation to their child's chronic health problem. Davis (1993), basing his framework on Kelly's notion of personal constructs (Kelly, 1991), considers the dynamic cognitive processes adopted by parents in relation to the way they view themselves, their children and the health problem. A number of constraints and resources that family belief systems have for family adjustment have also been proposed.

The remainder of this section will describe the influences on parental well-being proposed by these models.

*Disability-stress-coping model (Wallander et al., 1989)*

The Wallander et al. (1989) model suggests that parental well-being or stress is mediated by risk and resistance factors. These interact with each other to have both direct and indirect influences on parental coping and well-being.

In the most recent review of risk and resistance factors associated with parents coping with chronic paediatric health problems, Wallander and Varni (1998) concluded that neither the functional care strain of looking after the child nor objective measures of illness severity, correlated with adjustment. However, they suggested that everyday hassles and disability-related stresses, such as hospitalisation, influenced parental well-being. They recommend more qualitative investigations in order to identify what experiences families identify as stressful.

Resilience in the face of potential stressors is found to be mediated by problem focused coping methods where parents systematically attempt to address particular problems associated with their child's difficulties, as opposed to palliative-emotion focused coping. Lazarus and Folkman (1984) proposed that individual's perceptions of threat and loss associated with an event influence the coping strategy that may be chosen. Thus it is possible, that different strategies may be adopted at different times in relation to perceived threats. However, research investigating parental appraisal of particular threats or "illness" events (such as treatment in the course of their child's health difficulties), is lacking (Wallander et al., 1989).

Factors such as better family support, the availability of a large social support network and marital satisfaction have also been shown to be associated with greater parental well-being. More complex intra-personal factors and social processes such as the maintenance of hope (Horton and Wallander, 1997), have also been indicated as protective of parental well-being.

#### *Transactional stress and coping model*

The basis for the transactional stress and coping model was empirical evidence for processes which reduced stress and social processes that were hypothesised as appropriate targets for interventions (Thompson et al., 1994). These researchers found daily hassle related stresses, lower efficacy ratings and emotion focused coping, correlated with poor adjustment as well as low levels of family supportiveness and high levels of family conflict. In particular, low expectations regarding the efficacy of maintaining one's child's well-being in relation to their illness were found to be predictive of maternal anxiety.

#### *Trauma models*

In recent years, several research groups have proposed that the framework clinicians use when assessing post traumatic stress disorder (PTSD) in individuals who have survived a traumatic experience, may be appropriate when attempting to understand the emotional reactions experienced by families whose children have been diagnosed with disease or are hurt in accidents (e.g. Barakat et al., 1997; Stuber, Gonzalez, Meeske, Guthrie, Houskamp, Pynoss & Kazak, 1994). Recent additions to the Diagnostic Categories of the DSM-IV reflect the fact that in response to new research, PTSD is now more widely defined as resulting from witnessing or being exposed to "actual or threatened death or serious injury or a threat to the physical integrity of the self or others in which the person's response involves intense fear, helplessness or horror". Landolt et al. (1998) suggests that parents are likely to be both directly and indirectly affected by their children's accidents or illnesses as not only may they have witnessed the threat to their child but they may also be traumatised by their own experiences, such as guilt.

A study by Landolt et al. (1998), looked at the experiences of parents and children where the child had been involved in a traffic accident, had been burned or had a recent cancer diagnosis. They found that parents experienced PTSD symptoms, especially re-experiences or recurring images of events. Similarly, Barakat et al. (1997), found that the parents of cancer survivors

showed significantly higher levels of post-traumatic stress symptoms than parents of healthy children. The extent to which parents felt their child's life had been under threat in the past was associated with more severe symptoms. (Kazak, Stuber, Barakat, Meeske, Guthrie & Meadows, 1998)

The relative impact of the accident or illness diagnosis event compared to witnessing traumatic medical treatment on parental well-being is unknown (Landolt et al., 1998). Stuber, Kazak, Meeske & Baraket (1998) in a study of parents of paediatric cancer sufferers, suggest that the necessary involvement of parents in their child's treatment, whilst to some extent is empowering, often involves consenting to staff giving their child painful treatment. These researchers suggest that feelings of helplessness when a child is in pain and the belief that one needs to be hyper-vigilant to protect one's child "sets the stage for the development of hyper arousal and guilt". However, they also state that parents' responses are more likely to be determined by their subjective appraisal of events.

Clinical observations by Figley (1995), following a considerable body of work with traumatised families, led to him proposing that family members of a child victim of trauma may experience similar symptoms to those of a primary victim of trauma according to DSM-IV criteria. This author indicates that the focus of parents' and families' responses is unlikely to be the traumatic event itself, but associated with factors such as the possibility of the child dying, anxiety that the child may be permanently disabled or denial of potential consequences. These have been referred to as secondary or systemic traumatic stress (Barnes, 1995; Figley, 1998).

Barnes (1995), using a Delphi methodology to look at families' experiences of paediatric intensive care units, supported Figley's (1995) proposals. The results from his study also indicated that factors such as families' beliefs about their vulnerability, catastrophising about possible consequences of the child's injury and their ability to trust care givers, could be important mediators of family stress.

A more recent literature review by Barnes (1998) of clinical case studies of family responses to life changes and traumatic events, notes the emergence of a number of themes related to family or parental well-being. In common with the results of the Barakat et al. (1997) research, he proposes that the focus of parents' concerns is likely to be around the critical nature of their

child's condition. He hypothesises that parents' "world views" regarding safety and vulnerability may be altered and may influence traumatic stress sufferers' experiences of hopelessness and sense of self worth (Janoff-Bulman, 1992). Appraisals of stress are also considered to influence coping strategies, emotional sequelae and family interactional patterns and potentially the adoption of different roles by family members.

The literature pertaining to secondary traumatic stress or PTSD symptoms that parents experience as a result of their child's health difficulties, has yet to be developed. Factors which may be predictive of good or poor adjustment of parents have been suggested as perceived degree of life threat, global views regarding vulnerability and subjective appraisals of stress, but these have not been extensively researched. Influences from the existing PTSD research pertaining to mental health in individuals' direct experiences, would also suggest self-blame, hopelessness and social support to be important mediators (Joseph, 1999).

Subjective appraisals of stress and the resources available to cope, have been indicated as important by models when focusing on general stress-resiliency in parents of chronically ill children. They have also been suggested by research and clinical observations of parents whose response to their child's difficulties is similar to that suggested by trauma models. Influences on these appraisals may be pre-existing family beliefs or stories or constructs which have developed as the result of the difficulties. The role of beliefs is discussed briefly below.

#### *Beliefs, constructs and family stories as a constraint or resource*

Shaw and Halliday (1992) state that beliefs about the meanings of health and illness are particularly important and are embedded in family stories. They suggest that stories tie people to the past whilst helping them to understand the present. Similarly, narrative therapists such as White and Epston (1990), have suggested that the influence of stories that dominate individuals' explanations of the way the current situation is appraised. In other words, the familial or individual story that dominates, may preclude alternative ways of viewing the situation and different ways of responding as a result. Alternatively, these beliefs may prove to be useful and help families to maintain hope or devote their energies to meeting the challenge. For example, Figley (1988) observed that families able to recognise the strengths they have developed through their struggle, adjusted better to traumatic events.

Davis (1993) considers that parents' beliefs about, or constructs of, themselves, their children and illness, whilst relatively stable, are constantly bombarded by new information and experiences which need to be reviewed in relation to the existing construct system and possibly challenged. He suggests that parents may use their pre-existing ideas about illness to help them make sense of the situation and therefore, for example, trivialise a serious illness as they are used to considering the impact of less severe common childhood illnesses. Alternatively, parents who have always had fears for their child's health, may consider the diagnosis for their child as more threatening than it actually is and become extremely anxious as a result. Influences on parents such as the uncertainty of their child's prognosis and ideas about the future, are proposed as affecting parents' attempts to make sense of new situations.

### **Critique of research to date**

Overall, most studies of family adjustment to child burn injuries have been child focused. Some have attempted to investigate relationships between child adjustment and parental well-being but it remains unclear whether parents' difficulties are due to their children's adjustment problems or vice versa. Which aspects of family systems exacerbate or cause parental difficulties have also not been established (Meyer et al., 1994). Therefore, it is difficult to predict which parents may have greater support needs and what contributes to stress resiliency in those who cope well. There are indications that many paediatric burn patients come from families with pre-existing psychosocial problems, which may then be exacerbated following the injury (Kendall-Grove, Ehde, Patterson & Johnson 1998). Although this makes it difficult to delineate which aspects of parental well-being can be attributed solely to their child's injury, it does not preclude the need to understand those issues which parents perceive as most affecting their well-being in these circumstances and identify appropriate interventions.

The research which has considered parental well-being has been fraught with a number of methodological problems. A review of earlier research, indicates a failure to compare the results with control groups or match control groups on important variables. Further, they are mainly based on single clinician observations (Tarnowski & Rasnake, 1994). More recent studies have been cross-sectional in nature with only one longitudinal study available. This makes it difficult to compare the results of different researchers. In addition, sample sizes are generally small and

invariably drawn from a single clinic in one location.

More recent research has used a number of standardised measures including the Parenting Stress Index (PSI), the Beck Depression Inventory (BDI), and the Impact of Events Scale (IES), to assess parental distress. Potential difficulties have been suggested with all these measures. The PSI looks at stress in a very general way and was originally designed to be used with children under three but has been used in the burns literature with parents whose children span a wider age range. The BDI may be too insensitive to pick up indicators of mild depression (Oliver & Simmons, 1984) and IES includes items relating to sleep when sleep itself is likely to be disrupted anyway if caring for a young, ill child.

A more generalised criticism of the child and adult burns literature is that measures used may be inadequate to capture dimensions of distress caused by the injury and its consequences in the long and short term (Tarnowski and Rasnake, 1994). Limited attempts to understand parental adjustment following their child's burn injury have considered that generalised measures of distress may be appropriate (e.g. Meyer et al., 1994) but have also suggested that parental stress is more likely to be reflected in measures that focus specifically on anxiety associated with the injury event (Cella et al., 1988). Models which offer a framework which may facilitate our understanding of influences on parental stress, can be found in related areas of research. These include those which focus on stress resiliency in parents' responses to their child's chronic illnesses, trauma models and general approaches to understanding the management of stress by families. However, their relevance to paediatric burn injuries has not been systematically reviewed.

Gaps in the literature using the frameworks above include a poor understanding of what parents actually identify as stressful, more complex factors such as the role of hope in maintaining parental well-being, mediators of parental PTSD symptoms and parents' appraisal of illness events such as painful medical procedures. In addition, the focus is largely on using measures that capture the "deficits" that individuals or families experience rather than looking at which "deficits" may form part of adaptive responses over time or which illustrate family resilience.

Little is known about how parents experience their child's burn injury and treatment and what impact they perceive aspects of the injury and after-care as having on their well-being and that of

their family. The relationship between parental and child adjustment is unclear. Researchers in the field of paediatric burns, chronic illness and in the research related to treating trauma in families, suggest that the beliefs held or developed by parents around what they interpret to be threatening or helpful are likely to constrain or facilitate parental and child adjustment.

In common with other studies of the impact of chronic illness on families, it appears likely that there is a complex relationship between child and parental adjustment that may not be readily identified using combinations of standardised assessment measures without previous attempts to clarify risk and resiliency factors for parental adjustment. The aims of the proposed study are to establish what parents perceive as having influenced their well-being, taking into account not just the circumstances of the injury itself, but also subsequent treatment related events and indicators of child well-being that may or may not be perceived by parents as affecting their adjustment.

### **Summary of research aims**

This research aims to examine the views of parents with a range of burn and hospitalisation experiences in order to:

- explore parents' constructions of the experience of having a child who has been accidentally burned in terms of its perceived impact on their well-being;
- examine mediators of well-being identified by parents and to compare these with those posited by literature in related areas;
- investigate changes in the meanings parents attribute to their experiences over time and the consequences for parental well-being;
- explore the significance of parents' constructions of their child's adjustment since the burn injury for parental well-being;
- explore whether different types of involvement in their child's treatment was perceived as impacting upon parental well-being.

### **Rationale for using a qualitative research method**

The notion that parents' own appraisal of their situation plays a part in governing their adjustment rather than just objective measures of their child's condition is common to nearly all the models of parental adjustment discussed. It seems important to prioritise parents'



perceptions of the causes of their distress or well-being (child related or otherwise), and their appraisal of their coping resources, in order to identify patterns of problematic or protective beliefs that may affect long-term parental psychological outcome. As the suitability of a number of frameworks for investigating parental adjustment to burns has not been evaluated, an approach that is not specifically aligned to any of the models reviewed in the introduction is suggested.

Advocates of narrative therapy such as White and Epston (1990), concur that people continuously interpret their experiences and that the meanings that they distil from them influence their actions and further interpretation of their experiences. In the current study, the variety of ways in which parents attempt to make sense of (or “story”) what to others may appear to be a traumatic experience, is proposed as an important starting point when attempting to develop a model of parental adjustment to thermal injury. This builds a picture of what parents believe to be protective of, or detrimental to, their well-being.

In practice, accessing these aspects of parental responses to their child’s injury and their potential relationship to other variables, requires the use of an interview-based methodology (Tarnowski and Rasnake, 1994). Whilst standardised questionnaires are useful for producing results that are quantifiable and generalisable, they predetermine the context of what can be communicated (Richardson, 1996) and therefore are not appropriate for exploring parental views in an area of functioning that is as yet poorly understood. In contrast, qualitative research techniques are viewed as enabling a more detailed assessment of what parents understand to be important in these circumstances. They therefore guide future hypothesis generation on which to base relevant quantitative research. In attempting to understand influences on parental well-being, any number of the variables suggested by the conceptual models reviewed could be considered as relevant to an empirical study. However, as the relevance of these models has yet to be established and the limited existing research inconclusive as well as methodologically flawed, a more exploratory and flexible research method seems to be appropriate. Furthermore, indications from researchers using the existing models are that the depth of our understanding of some of the more complex processes involved in mediating parental adjustment to a paediatric health problem, may be increased through using methodologies that prioritise parents’ subjective reports.

For example, after the event one parent may consider themselves lucky that their child escaped worse injury and feel that they have gained somehow from the experience, whereas another may construe their inability to prevent their child's accident as an indicator that they will never be able to protect their child in the future. Accessing such appraisals through quantitative methods is thought by some researchers to miss the richness and complexity of the spontaneous assessments people make of the meaning of a traumatic event for themselves and others (Joseph, 1999).

A research methodology that emphasises the individual's attempts to find meaning in a particular phenomenon in the context in which they experience it, as well as allowing for the identification of what parents describe as influencing their well-being and how these influences affect them, was therefore seen to be most appropriate. Whilst research methods referred to as qualitative, embrace ideas and techniques that are derived from a wide range of disciplines, they appear to have a number of features in common (Mason, 1996). All are concerned with how the social world is interpreted, understood, experienced or produced. Data generation methods endeavour as far as possible to be sensitive to and remain close to "real life" experiences and are concerned with producing detailed results which enable greater understanding of a phenomenon as it is experienced in particular social contexts.

### *Phenomenology*

A phenomenological approach to qualitative research proposes that the researcher attempts to determine what the everyday lived experience of the phenomenon under scrutiny means for individuals and attempts to distil the essence of the structures of the experience (Moustakas, 1994). The focus of the current research is to explore what beliefs underlie parents' understandings of their experiences and how they perceive their experiences to be relevant to their well-being. A particular phenomenological approach, interpretative phenomenological analysis (IPA), has been chosen to aid this as it proposes a link between verbal explanations and the cognitions with which they may be associated.

### *Interpretative Phenomenological Analysis (IPA)*

IPA draws not only upon ideas from traditional phenomenology but also from the notion of symbolic interactionism (Smith, 1996). Advocates of this school of thought argue that social scientists should consider the meanings people attach to events as central to attempts to

understand their social world. Access to these meanings is felt to be dependent upon the researchers own ideas as these allow the investigator to make sense of and try to interpret another person's world (Smith, Jarman and Osborn, 1999).

Recently IPA has been most commonly used in the field of health psychology (e.g. Osborn and Smith, 1998). Smith, Jarman and Osborn (1999) suggest that using IPA in relation to health problems is useful, as "real entities" such as an illness, provide a backdrop against which to consider personal accounts of physical processes. They give the example of exploring how two patients with the same illness talk very differently about the same condition, in order to elucidate the perceptual processes that individuals use or share, to make sense of their illness. As the current study proposes to investigate parents' perceptions of complex influences and cognitive processes that aid or hinder adjustment to their child's injury, this was felt to be an appropriate methodology. In order to highlight potential differences and strengthen claims for the commonality of the strategies parents' use to make sense of their experiences, a specific sampling approach was used to access a wide spectrum of parents. This is discussed in more detail in the method section.

## Method

### Design

The research methodology identified as most appropriate for the study was Interpretative Phenomenological Analysis (IPA) (Smith, 1996). The analysis of transcriptions resulting from semi-structured interviews with parents focused on their attempts to make sense of the burn event itself, the hospitalisation of their child and subsequent treatment. Beliefs about the impact of the experience on their child were also drawn out and the potential consequences for parents explored.

In order to gain an understanding of how parents adapted to the burn event under different conditions, a maximum variation sampling strategy was employed. This method of sampling is described in more detail under the participants section. In this way, both variations and important common patterns could be examined.

### Ethical approval

Prior to identifying and approaching potential participants, ethical approval was obtained. This entailed submitting a research proposal first to the Trust Research Committee and following their approval to the local Paediatric Research Ethics Committee. Permission was obtained from both committees (see Appendix 1).

### Participants

#### *Selection criteria for inclusion*

- Parents whose child was aged five or under at the time the thermal injury occurred
- Parents whose child was admitted to the burns unit of a children's hospital for more than one night with the primary diagnosis recorded as a thermal injury
- Parents whose child had been injured within the last two years and for whom formal outpatient follow-up was planned

### *Selection criteria for exclusion*

- Parents whose child's injuries had been identified as, or were suspected to be, non-accidental
- Parents whose child had other chronic illnesses or disabilities pre-dating the thermal injury

To ensure that parents had experienced the phenomenon under scrutiny, it was decided to approach young children who were still largely dependant on parent's care and who required their support whilst in hospital. It was felt that if the injury was of sufficient severity for a child to be admitted overnight, parents would also be likely to experience at least some of the same hospital related phenomena. The practicalities for approaching parents required that they were still being seen by hospital staff. The two year time period was chosen as most parents were still likely to be involved with clinic appointments during this time. Although the possibility that pre-existing difficulties in the family could influence parental well-being, ensuring that the child did not have another chronic illness to which these difficulties could be attributed was felt to be important.

### *Sample size*

Researchers experienced in the use of IPA make a variety of recommendations for maximum sample size. Recommendations are based on the practical constraints of doing in-depth iterative analyses. Phenomenological researchers have used different sample sizes. For example, Dukes (1984) used one, three and ten participants in his series of studies. Other researchers such as Rieman (1986), used ten. In a discussion of different sample sizes used in this type of research, Creswell (1998) recommends a sample size of ten as reasonable.

In line with other phenomenologists, a purposive or theoretical strategy for sampling was chosen in order to select parents for this research. This was to help ensure that as far as possible, the particular phenomenon under scrutiny was represented in the sample. The strategies chosen were "maximum variation" and quota sampling. These are described in the next section.

### *Sampling strategy*

In general, researchers using qualitative methods are not driven by the need to confirm the 'representativeness' of the sample they have selected as required by statistical data analysis. Instead, the aim is to provide an "understanding of the conditions under which a particular finding appears and operates" (Denzin and Lincoln, 1998, p.204), and to use data from the sample to illustrate how and under what accompanying conditions a phenomenon occurs.

Little information exists regarding how parents experience the practical and emotional sequelae of their child's thermal injury and what circumstances influence their appraisal of the event and its consequences. Therefore, it seemed important to select a sampling strategy that allowed the identification of important patterns common to all the experiences across diverse circumstances.

A "maximum variation" sampling strategy was selected as it entails actively looking for outlier cases to see whether the same underlying patterns still hold (Miles and Huberman, 1994). This seemed to be an especially appropriate strategy to use in conjunction with a phenomenological approach to collecting and analysing qualitative data, which emphasises the search for the "invariant structure of the experience recognising that a single unifying meaning of the experience exists" (Cresswell, 1998, p.54).

It is clearly important to be systematic about making decisions about sampling practice alterations such as those required by a maximum variation sampling strategy. It was therefore decided to adopt the recommendations of researchers such as Mason (1996) to use a quota sampling strategy such that the sample was systematically varied along important dimensions (see Table 1).

**Table 1** - Quota target list for recruitment of participants

At least 2 families who were considered by hospital staff to have coped well and whose children had experienced <b>less</b> than 10% total body surface area burns.
At least 2 families who were considered by hospital staff not to have coped well and whose children had experienced <b>less</b> than 10% total body surface area burns.
At least 2 families who were considered by hospital staff to have coped well and whose children had experienced <b>more</b> than 10% total body surface area burns.
At least 2 families who were considered by hospital staff not to have coped well and whose children had experienced <b>more</b> than 10% total body surface area burns
Of the above at least 2 families whose children <b>had</b> required skin grafts and at least 2 families whose children <b>had not</b> required skin grafts.

Mason (1996) states that attempts at theoretical or purposive sampling such as the strategy described above should be “viewed more interactively” in order to incorporate influences that were not predicted earlier in the process. To ensure that this is not approached in an ad hoc manner, Mason’s suggestion to set an initial tentative data/quota target that can be revised if required, was incorporated into the sampling strategy for this research. In addition, the sampling strategy was reviewed at intervals during the data collection/analysis process. It was decided to aim for the quota targets listed in Table 1 in order to generate descriptions of a range of experiences.

The focus of these initial data targets and decisions regarding the dimensions along which maximum variation sampling should vary, were determined prior to sampling. This was done through a review of relevant research in this area and discussions with hospital staff and in consultation with parents from the time of the injury itself until the child was discharged from treatment. Treatment experiences for children whose thermal injuries covered a total body surface area greater than ten percent differed from those with burns covering a less extensive area. For the former children, fluid resuscitation was required for 72 hours following admission to prevent potentially fatal levels of fluid loss through the dermis of the skin. It was hypothesised that this may increase parents’ perceived threats to their child’s integrity and influence their appraisal of circumstances surrounding their child’s injury and hospital admission. Therefore, the first dimension chosen was whether a child’s burn fell in the above ten percent or below ten percent category.

Research focusing on parents’ experiences of paediatric chronic illness does not suggest that severity of a condition per se influences well-being. Instead, the way in which the child’s illness is appraised has been associated with how parents cope (e.g. Thompson Gustafson, Hamlett & Spock, 1992). Wallander and Varni (1998) pointing out stress processing theories, suggest that the coping strategies used and ultimately the impact of a particular event on well-being would be influenced by perceptions of threat, loss and the challenges associated with a particular event. It was hypothesised that common patterns that underlie the processes involved in managing the impact of the injury on parental well-being may be identified by selecting parents who appeared to be coping well or poorly in the face of contrasting treatment requirements necessitated by different levels of injury severity. However, it was not assumed that the attributes that caused families to be identified as “good” or “poor” copers were stable. One of the aims of the research was to explore how families understood changes to their well-being over time. In addition, it was

not presumed that staff could provide a definitive measure of coping but it was acknowledged that the staff who were regularly in contact with participants were best placed to provide a consensus judgement about participants' well-being. Therefore, the second dimension chosen, was whether on last contact with staff, parents were perceived to be coping well or poorly.

Different treatment experiences were also identified by the first two parents who were interviewed. Their children had experienced burns of different depths although both had roughly equivalent total body surface area burns. The child with a deeper burn required skin grafting which involved numerous trips to the operating theatre, whereas the other had been discharged from hospital as soon as his wound had begun to heal. Therefore, the last quota target was added to the list.

#### *Method for recruiting participants*

This was done in the following six stages.

- The researcher met with all staff involved in in-patient and out-patient care on several occasions to discuss the purpose of the study, gather information regarding accessibility of patient information and to consider practical arrangements for recruiting participants.
- Initially nursing staff running the scar management clinic, post discharge dressing clinic and those in charge of providing in-patient care were provided with a list of criteria for recruitment of participants (see Appendix 2) and asked to identify parents for potential inclusion in the study. Having checked records they were asked to discuss with each other their impressions and recollections of parents and consider how they were currently perceived as coping.
- Prior to approaching parents, staff were asked to provide the researcher with details of the child's date of birth, total body surface area burned, skin graft requirements, whether parents were currently coping well and approximate time since discharge from in-patient care. This was done in order that a record of parents who had been approached could be kept so that the focus of sampling could be altered in line with the requirements of the sampling strategy.
- Parent(s) were then approached via letter. Each parent was sent a covering letter from their consultant introducing the researcher, a letter with a reply slip attached from the researcher and an information sheet describing the study and offering contact numbers for further information (see Appendix 3). Parents were asked to return the reply slip to the researcher in a pre-paid envelope if they were interested in participating, providing their names and a contact number.



- Each parent was then contacted by the researcher and a mutually convenient time and place for interviews arranged. The researcher was careful to explain the voluntary nature of the parents participation and that their anonymity would be maintained.
- Towards the latter stages of recruitment, when the sampling strategy required the more specific criteria to fulfil the quotas initially identified, staff were asked to focus the search for particular groups of parents.

#### *Ethical considerations when recruiting participants*

Following lengthy discussions with medical staff and the Clinical Psychologist who provides support for parents admitted to the burns unit, it was decided that parents would not be approached whilst their children were still in hospital in order to minimise the risk of making distressing demands on parents. As a further precaution, no parents were approached until their child had been discharged from in-patient care for at least one month.

Participants were assured that every effort would be made to ensure that their identities or circumstances that might identify them would not be discernible from the final report and that the contents of their interviews would not be discussed with medical staff or services. Participants were then to sign a consent form (see Appendix 3).

Due to the potential of the interview for identifying distressed individuals, arrangements were made with the hospital psychology service to receive referrals if required.

#### *Participant details*

All but one of the participants were parents of children who had been admitted to the Burns Unit at a children's hospital. One participant had been admitted to another ward at the hospital due to the unit's temporary closure following the outbreak of a contagious virus.

No lone parents took part in this study; all were living with partners. Five parents chose to be interviewed together and five mothers were interviewed alone. The time since the child was injured ranged from six months to 26 months.

The age at which the children were injured ranged from nine months to three years and six months.

**Table 2** Information about participants

<b>Participant number &amp; Child pseudonyms</b>	F1 John	F2 Lenny	F3 Karen	F4 Robert	F5 Sarah	F6 Harriet	F7 Elizabeth	F8 Toby	F9 James	F10 Kevin
<b>Parent(s) interviewed M = Mother F = Father</b>	M,F	M,F	M	M,F	M	M,F	M	M,F	M	M
<b>Age of parent(s)</b>	20 23	37 39	30	27 30	25	37 40	37	32 32	31	33
<b>Current age of child Y = year M = month</b>	2y 3m	2y 11m	4 1m	3y 10m	1y 4m	2y 6m	2 3m	2	1y 10m	3
<b>Age of child when injury occurred</b>	1y 4m	2	3y 6m	1y 10m	9m	1y 6m	1y 6m	1y 6m	1y 4m	2y 6m
<b>Total body surface area burned (over/under ten percent)</b>	over	under	over	over	under	under	Over	under	over	under
<b>Skin grafts required</b>	Yes	No	Yes	Yes	No	No	No	No	No	No
<b>Observed as "coping"</b>	Yes	No	No	Yes	Yes	No	No	Yes	No	Yes

## Measures

### *Developing the interviewing schedule*

The aim of this research project was to investigate parents' appraisals and lived experience of the event of their child's injury and after-care. Therefore, it was imperative that the interview process remained flexible and allowed individuals to lead the interview to areas they perceived as important. Both Mason (1996) and Smith et al. (1999) outline the construction of "loose interview" formats that enable the interviewer to explore the experiences of individual participants, whilst also attempting to elicit information that is related to the overall research question.

The interview schedule was developed with reference to the available research literature. The aim of developing the interview schedule was to sensitise the researcher to areas that *might* be of relevance to the research question but which was by no means viewed as an exhaustive list of

questions (see Appendix 4 for a copy of the schedule). It was also aimed at helping the researcher reflect on what significance the interview process and questions may have for the participants (Schur, Gamsu & Barley, 1999).

Questions were based on areas identified by existing models as important in the adjustment of parents of children with chronic illnesses and thermal injuries. They were focused on the impact that parents perceived the child's burn had on their child, on their family, on their own well-being and on the relationships between these issues. The following areas were explored -

- Injury and hospitalisation circumstances
- Perceptions of the nature and severity of the child's injury
- Perceptions of the impact of the injury on their child over time
- Perceptions of the impact of the injury on themselves and the rest of their family over time (including the impact of treatment)
- Experiences and expectations of discharge from hospital and rehabilitation
- Perceived impact of injury on parenting
- Coping strategies employed over time
- Expectations for themselves and their child in the future

In addition, each interview began with questions aimed at gaining demographic details from parents about themselves and their children to facilitate the building of rapport. Each interview ended with questions that were aimed at establishing some idea of how parents had experienced the interview and identifying the need for further support.

From the outset it was acknowledged that a phenomenological approach to qualitative data collection entails developing some questions for topics to be addressed in the interview but is committed to examining the meaning of experiences for individuals (Creswell, 1998). Questions were framed so as not to lead the participant in their discussion of the areas identified and were designed to be open and initially broad. For example, participants might be initially asked "What was it like when [child's name] was in hospital?" rather than "Was it difficult when [child's name] was in hospital?" If participants did not respond or were unsure what the researcher meant by the question, it was followed up by a more specific question such as "What were you most concerned about when [child's name] was in hospital?"

## Procedure

### *Interviewing Procedure*

At the beginning of each interview, the areas outlined on the patient information sheet were reiterated with the participants. Participants could choose to say as little or as much as they wanted in relation to questions asked, they could stop the interview at any time, that with their permission the interview would be audio- taped and that their anonymity would be maintained as far as possible (see *Ethical considerations when recruiting participants* p.26 for a more detailed discussion of this issue). The purpose of the research was also explained again to participants. Following this they were asked if they still wished to take part in the research and were asked to sign a consent form (Appendix 3).

Smith et al. (1999) recommends that the interview schedule be used as a guide to “ take the respondent through relevant territory” but that “ how the territory is covered is co-determined by the investigator and respondent together”. This strategy was adopted by the researcher in that the areas identified by the schedule were only used as a rough guide. For example, the order in which the question areas were addressed was adapted according to the particular participant and the extent to which these areas were probed was dependent on the participant’s response. The researcher also aimed to minimise the use of prompts, especially if participants chose to go into a particular area in detail (Smith et al., 1999).

Each participant was involved in one face to face interview. Interviews lasted between one and a half and two and a half hours. All interviews were carried out in the participants’ homes. After the interview, participants were told that a short summary of their interview would be sent to them following transcription and analysis of the transcript. Consent was then obtained to contact the participants again to arrange a time for the researcher and participants to reflect on their understanding of the area under investigation once the participant had received an interview summary sheet. Careful attention was paid to the phrasing of the summary sheets so that the language was familiar to the participants and could be easily related to the interview (Miles & Huberman, 1994). An example of one of the parent’s summaries can be found in Appendix 5.

Approximately three months after the interview participants were contacted by telephone and participants’ reflections on the analysis and research process discussed. Following these

telephone conversations, participants' annotations and additions (based on the researcher and participant's discussion) were then made to the transcript along with their implications for the themes. This process was viewed as an opportunity to verify analyses of the data.

#### *Transcription and note taking procedures*

Each audio-tape of an interview was transcribed verbatim. Pauses or silences of longer than a few seconds were labeled (pause) and situations in which the speaker was interrupted or did not finish their sentence were denoted with (...). A row of question marks was used when the researcher was unable to hear what the participants were saying.

Verbal intonations and other non-verbal behaviours such as facial expressions or one parent comforting the other, were noted next to the transcribed speech to which it pertained.

During each interview and immediately after each interview the researcher made notes of particular facial expressions or emotional reactions, her overall reflections on the interview process, any reflections on her own response to the material and any ideas regarding how she was perceived during the interview process. These notes were then also incorporated into the data analysis.

#### **Data analysis**

The philosophical underpinnings of the IPA approach are explained more fully in the introduction section. In brief, phenomenology proposes that individuals' interpret their own world to make it meaningful and that these interpretations are the individuals reality. Researchers such as Bryman (1988) therefore suggest that it is necessary to try and understand individual interpretative processes in order to understand their experiences. A connection is presumed between the meaning of an experience to an individual, the verbal information they offer when interviewed and the perceptual processes that underlie that information (Smith et al., 1999).

Smith (1996), acknowledged that the researchers' analysis, whilst trying to promote and prioritise the participants perspective (by as far as possible putting her own perspectives on the phenomenon to one side), can only be done through the interpretative work of the researcher. In other words, the researcher inevitably uses her own experiences and interpretative processes to try to understand somebody else's experiences (Schur et al., 1999).

The researcher for this project felt it was particularly important to raise her awareness of and bracket her own ideas regarding the phenomenon prior to the analysis (Creswell, 1998). This was done through supervision discussions after the first reading of the first interview (also see Appendix 7b).

The process of interpretative phenomenological analysis was then carried out according to the procedure described by Smith et al. (1999). One interview, in this case the first interview, was chosen to start the analysis. The transcript for this interview was read carefully and notes were made in the left-hand margin about statements that appeared to be related to the phenomenon under scrutiny. If both parents were interviewed together, notes were also made about patterns of interactions between them as observed in the transcription.

Subsequently, the interview was re-read and significant statements were highlighted. The possible meanings extracted by the researcher were then listed next to the relevant highlighted text in the right hand margin (see Table 3 for an example).

**Table 3 - Example of initial coding procedure**

Notes	Text excerpt	Meanings/Sub-themes
Blames self as parent	<i>M: Cos I never ever thought it would happen to me cos I am a very careful mum. I'm always there for them so I never ever thought it would happen to me.</i>	
View of children's vulnerability heightened and ability to keep them safe challenged	<i>... I was talking to C**** one of the nurses and I was saying I don't think I'll be able to cope cos it questions like being a mum and everything, it's just going through your head that you can't be a good mum cos you let your daughter burn herself</i> (shaking voice and nearly crying) <i>just things like that.</i>	Self blame/guilt
Distressed / guilt remains	<i>I: Do you still have those thoughts now?</i> <i>M: Yeah that's why I can't let them out of my sight</i> (shaky voice and crying). (Text Units 419- 420 and 423-424)	Concerns about safety

Next, these meanings/sub-themes were listed on a separate piece of paper. Connections between them were examined and any meanings/sub-themes that appeared to form clusters, were grouped together with a view to identifying sub and super-ordinate themes. A list was then drawn up of the super-ordinate themes with the meanings listed beneath them (See Appendix 6a). The process

up to this point was reflected upon in supervision and emerging ideas incorporated into the analysis process. At this point, the organisation of sub-theme clusters under the super-ordinate themes were also revised as it appeared that many threats and coping strategies remained stable over time (see Appendix 6b).

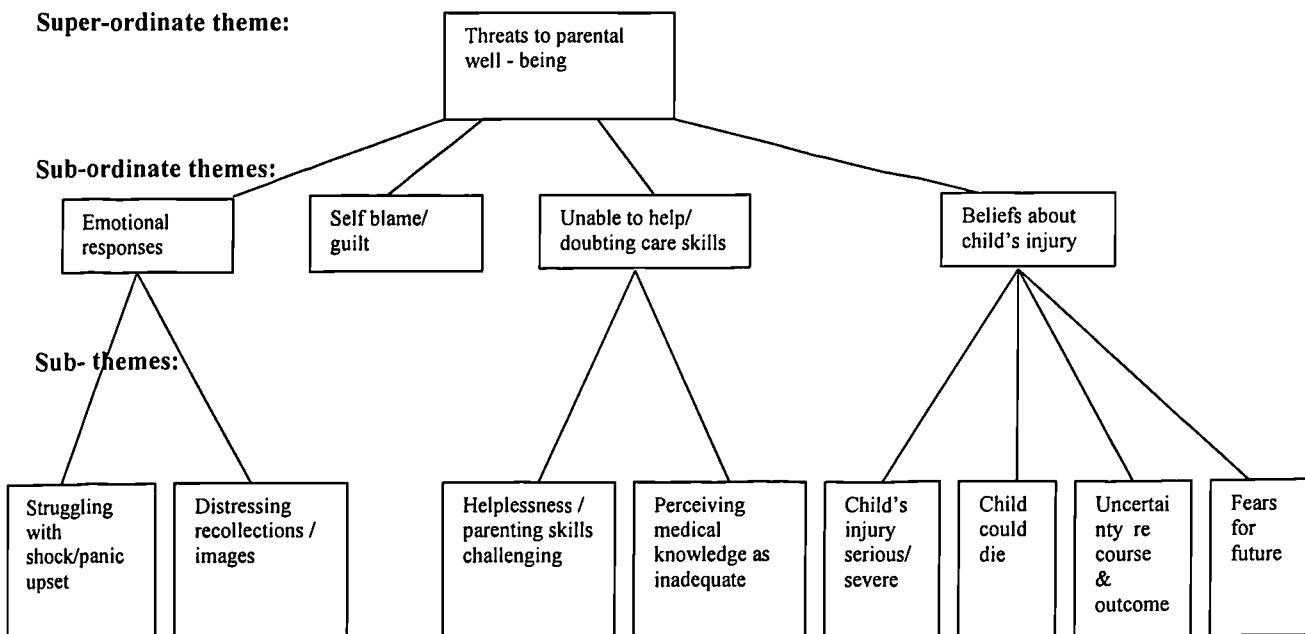
The process above was repeated for the second transcript as it was felt to be important at this stage to identify processes that may be relevant across cases. A second master list of themes was drawn up and compared with the first. These two lists were then merged. This effectively meant that some extra meaning categories/sub-themes were created and other categories felt to be replicating those identified in the first interview, removed or subsumed (see Appendix 6c). Following analysis of the second transcript, sub-themes were grouped under relevant sub-ordinate theme headings (see Table 4 and Appendix 6c).

**Table 4 - Grouping of meanings/sub-themes under sub-ordinate themes**

Text	Original list of meanings/sub-themes	Sub-ordinate themes
<i>M: You are just on automatic pilot aren't you you just go through the emotions you do what has got to be done.</i>	Cutting off from emotions/auto-pilot	Distancing self from emotions generated by accident and its consequences
<i>F: Getting there, being there as long as you can, and then the in-between times being busy I just don't want to know, want everyone to just get out the way, I want to just get on and do what I want to</i>	Cutting off from emotions/auto-pilot	Distancing self from emotions generated by accident and its consequences
<i>I: How do you think being burned has affected John. Do you think it's affected him at all?</i>	Explaining away impact on child	Distancing self from emotions generated by accident and its consequences
<i>M: Not at all (said with certainty) ...Not now.</i>		
<i>F: I think he was too young for it to affect him but it might do when he gets older and starts mixing with other kids it might do</i>	Fears for the future	Beliefs about child's injury

The researcher then loaded the new list of meaning/sub-theme categories into the NUD\*IST - 4 software package (QSR, 1997) to make an "index tree" – a list of sub-themes organised under sub-ordinate theme headings which in turn were grouped under the overarching super-ordinate themes that had been identified thus far (see Figure 1).

**Figure 1 - Example of sub-ordinate themes under-pinned by sub-themes**



The transcripts were then also loaded in to NUD\*IST - 4 (QSR, 1997). The units of text containing significant statements that had been highlighted in the text were then copied and pasted into the appropriate meaning category/sub-theme.

The procedures above were adopted for each of the transcripts although new master lists were not created each time. Instead, the highlighted statements from the transcripts were transferred directly into the appropriate meaning category/sub-theme in NUD\*IST – 4 (QSR, 1997) if it existed. However, if statements appeared not to cluster around existing sub-themes yet on examination had shared features, a new sub-theme was created in the index tree. This sometimes necessitated splitting a sub-theme to form two or more new sub-themes. Similarly, new sub-ordinate theme headings were created under which emerging sub-themes were listed if necessary. (See Appendices 6d and 6e for key changes to index trees made after analysis of subsequent interview transcripts). In both instances it was important to then check back to previously read transcripts to see if these categories had been represented in them as well.

When this process was complete, contents of each sub-theme were reviewed for each participant and duplicated statements pertaining to the same sub-theme removed. The clustering of sub-themes into sub-ordinate themes was also reviewed alongside the original transcripts and the



richness of material supporting these themes considered. The importance of different themes for the group as a whole was then ascertained and sub-themes were merged, subsumed under a different sub-ordinate theme or removed accordingly. The final list of themes was then generated such that a coherent account of the parents' stories could be provided (see Appendix 6f).

#### *Validity/Verification of data*

Establishing the credibility of qualitative research and verifying the results obtained clearly requires very different methods to those required of quantitative data. The philosophical underpinnings of most qualitative research are "broadly interpretivist" and are therefore not aimed at obtaining objective truths about the issue under investigation (Mason, 1996). However, validity checks are particularly important in this type of research to demonstrate to the reader that the researcher has not let their own preconceptions skew the representation of the participants' views. Researchers such as Osborn and Smith (1998), suggest therefore, that it is important to present enough verbatim data and indications of its connections with the researchers' interpretations for the reader to be able to evaluate the interpretation. This recommendation is considered in the presentation of the results section where attempts are made to guide the reader through how statements have been assigned to meaning categories and how these are then clustered around themes.

In order to guard against biases in interpretation and check the validity of the analyses, the following checks were used in this project.

- Firstly, the researcher used the process of "member checking" identified by Miles and Huberman (1994). The particular method she chose to employ was similar to one used in another phenomenological study (Melnick & Beaudry, 1990), which involved sharing individual analyses of transcripts with participants. Melnick and Beaudry (1990) showed copies of the transcripts to participants along with annotations and further questions. In the current study, whilst it was felt to be important to present participants with individualised analyses, it was also recognised that in order for people to make sense of what were often very long and not particularly coherently told stories, short summaries of proposed interpretations would be more appropriate.
- Secondly, the researcher asked two other people to read the first two transcripts and highlight what they saw as significant statements. These were then compared with the researcher's interpretations.

- Finally, the researcher prepared a list of significant statements and a separate list of meaning categories. Two other researchers were then invited to assign them to what they felt was the appropriate meaning category.

## Results

Following analysis of the interview transcripts using interpretative phenomenological analysis (IPA), two groups of themes emerged – those which were related to threats or perceived threats to individual parents' well-being and those which were related to attempts to cope with these threats

The super-ordinate themes identified relate to

- 1 Intra-personal sources of threats to parental well-being
- 2 Inter-personal sources of threats to parental well-being
- 3 Other threats to parental well-being
- 4 Strategies for coping with threats to well-being

The first theme considers those threats to well-being that parents identified in relation to their beliefs about their reaction to their child's injury and after-care, in terms of their own emotional response and beliefs about the effect of the injury on their child. The second theme concerns threats which are associated with other people's reactions to the injury, including the child themselves, or beliefs that parents hold about other people's responses. The third theme concerns threats arising from parents' experiences of particular circumstances associated with the child's accident, subsequent care requirements or pre-accident difficulties. The final theme relates to the coping strategies used by parents and families in order to manage these threats. Each super-ordinate theme is comprised of a number of sub-ordinate and sub-themes.

The analysis suggested links between particular threats to parental well-being and strategies for coping. However, these relationships are complex and dynamic, with different threats and coping strategies predominating at different times. The results section begins with a detailed description of the super-ordinate, sub-ordinate and sub-themes identified and variation within these themes. It is followed by an overview of the association between threats and coping strategies and their stability over time. Each super-ordinate theme description (numbered 1 to 4) will begin with a list of associated sub-ordinate themes (numbered 1.1, 1.2 etc., depending on the super-ordinate association), followed by an exploration of the sub-themes (shown in bold type).

that cluster under these sub-ordinate themes. For example, the super-ordinate theme 1 'Intra-personal threats to parent well-being', is made up of four sub-ordinate themes:

- 1.1 Emotional responses
- 1.2 Self blame/guilt
- 1.3 Unable to help/doubting care skills
- 1.4 Beliefs about child's injury

Three of these sub-ordinate themes consist of two or more sub-themes. For example, sub-ordinate theme 1.1 'Emotional responses', comprises two sub-themes: **Struggling with shock, panic and upset** and **Distressing recollections/images**.

In order for the reader to be able to evaluate the researcher's interpretation and clustering of data around particular themes, verbatim excerpts from the parents' reports will be presented alongside these descriptions. To maintain the anonymity of participants, identifying information has been removed and names of children replaced with pseudonyms.

To offer some indication of the most commonly identified links, an overview of the possible associations between the threats parents perceived to their well-being, the methods they used to manage these threats and their process of adjustment will be presented following the detailed analysis. Two summaries will be presented. Firstly, the connections between the super-ordinate theme, sub-ordinate theme and sub-themes relating to threats and coping will be presented in the form of a table. Secondly, the stability of threats and coping strategies over time is considered.

## Detailed Analysis

### Super-ordinate theme 1: Intra-personal threats to well-being

Four sub-ordinate themes were identified by families concerning their beliefs about their own reaction to their child's injury and after-care:

- 1.1 Emotional responses
- 1.2 Self blame/guilt
- 1.3 Unable to help/doubting care skills
- 1.4 Beliefs about child's injury

#### 1.1 *Emotional responses*

**Struggling with shock, panic and upset** appeared to be predominant features of all the parents' early experiences of their child's thermal injury. These emotions were most commonly described immediately following the accident and when their child was initially admitted to hospital. They described struggling to control their emotions while trying to respond appropriately to the situation despite feeling panic stricken or crying. Karen and Lenny's mothers offered the following descriptions of their experiences:

*M: In case you know, she could have gone up really and I just pulled the dress off and err, put a towel round her and brought her down. She didn't cry, you know. I was so upset, I was screaming and panicking and she didn't cry once. She stood by the phone while I phoned next door to come here... (Text unit 162)*

*M: But then I brought him downstairs and got the pressure cooker out and filled it with cold water and kept sponging him. You know I couldn't really tell what area it was on. I could see a bit on his cheek here and kept on doing that. I tried to calm him down and keep myself calm and then they had to ring back because of the address, it was a new estate. Are they coming, are they coming? So that's really how it went. (Text unit 99)*

Six parents also described **distressing recollections/images** of their experiences with their child. For three parents, these took the form of intrusive flashbacks and nightmares. These recollections appeared to be made more vivid by the interview process and in all cases resulted in participants becoming distressed. Four participants found their distress to be associated with particular sights and sounds that occurred around the injury event, whereas the other two found recalling the time they spent with their child during skin debridement (scrubbing off blistered skin) painful.

John's father described a recurring nightmare:

*M: It was when they took him in to the room to clean his skin that it was particularly hard for him [referring to partner]. (Text unit 239)*

*F: You were sat there on your own and he was saying dad, dad, dad and you just want to cuddle him sit with him but ....*

*M:... at night you could feel him jump up [referring to partner's nightmares]. (Text units 241-243)*

In common with other parents, Robert's mother found the first sight of her child's injury particularly distressing:

*M: (crying)*

*I: It sounds difficult to talk about ... Do you want to take a few minutes? I know as you've been talking it's really hard but is there a particular bit that made you upset, a particular image?*

*M: It was him standing in the bath pulling his skin off his arms. (Text units 90-92)*

In general, reminders generated by the interview process and other situations appeared to be particularly significant for the families. All but three participants became observably distressed during their recollections at interview and requested that the interview be suspended for a short period. Four participants also described other reminders as upsetting, such as revisiting the hospital or returning to the room where the accident happened. Sarah's mother found returning to the house after hospital distressing:

*M: Well as soon as I walked in well I burst into tears again cos I could see her foot print in the coffee where she had spilt it so I had to wash that first. (Text unit 440)*

Kevin's mother found the daily sight of her son's scar a distressing reminder:

*M:...But with Kevin it's like everyday it's a constant reminder because of the scarring there ... But looking at Kevin it's like a constant reminder, there's no getting away from it you have to be so careful with...(Text units 170)*

The impact these reminders had on parents seemed to be short lived for the majority of participants. Three parents however, continued to feel they presented a threat and two took care to avoid them (see Section 4.1).

## 1.2 Self blame/guilt

Feeling responsible in some way for their child's injury was a common theme for participants and compounded parents' distress both in the short and long term. Beliefs ranged from general feelings of guilt for three participants to beliefs that they could have prevented the accident in some way for three other parents.

*M: Yes and then he finally turned round the Russian doctor he said obviously a very, very bad accident. He said I hope everything goes alright for you he said that as we we're going out and I thought oh god and I felt guilty didn't I say I feel guilty for this? [said to partner]. (Text unit 142)*

Three parents articulated their belief that their child's accident indicated that they had failed in some way as a parent. These beliefs seemed to be experienced by all the parents at some point. However, a number of coping strategies ameliorated this belief over time for all but one of the parents. Sarah's mother described how her questioning of her parenting abilities continued:

*M: Cos I never ever thought it would happen to me cos I am a very careful mum. I'm always there for them so I never ever thought it would happen to me ... I was talking to C\*\*\*\* one of the nurses and I was saying I don't think I'll be able to cope cos it questions like being a mum and everything, it's just going through your head that you can't be a good mum cos you let your daughter burn herself (shaking voice and nearly crying) just things like that*

*I: Do you still have those thoughts now?*

*M: Yeah that's why I can't let them out of my sight (shaky voice and crying).*

(Text units 419- 420 and 423-424)

### 1.3 Unable to help/doubting care skills

As well as feeling in some way responsible for their child's accident, two sub-themes were identified in relation to parents' concerns about their abilities to help or care for their child. Seven parents described initially feeling overwhelmed by **helplessness** as they perceived themselves as unable to do anything to help their child and found their normal **parenting skills challenged**. These feelings were particularly intense when their child was first admitted to hospital but were also experienced by one parent following discharge. These feelings were discussed by John's father:

*F: ...do the best you can there's not a lot you can do you are so powerless you know there was nothing I could do... (Text unit 238)*

Similar experiences were also exemplified by Sarah's mother's comment:

*I: Mmm so how was it being with her in the room, [when her daughter was initially admitted to hospital] how did you find that?*

*M: I felt like I weren't a mum, like they were taking over cos they were doing everything for her.*

*I: So what sort of stuff was that?*

*M: just changing her bandages and things like that*

*I: So doing lots of treatment kind of things ....*

*M: But for like eight years no one's done that I've always done everything for them.*

(Text units 280-285)

Difficulties in carrying out care skills that parents had confidently managed prior to the accident also seemed to be a source of threat to parental well-being. These difficulties included being unable to physically comfort their child as described by John's mother:

*M: I wanted to pick him up and lie around in comfee chairs and you'd go in and they'd lift him out and I felt helpless because I couldn't move with him but it was nice to be able to hold him but that was about three weeks later... it was just frustrating that I couldn't pick him up when I wanted to and take him around, I just wanted him home. (Text unit 395)*

Others, such as Toby's mother, remembered:

*M: When I was trying to feed him he didn't like me trying to feed him and I couldn't hold him properly on my knee because of his bandage... feeding was a nightmare, couldn't get him to eat anything because it wasn't in a way that he was comfortable. So that was a bit difficult. (Text unit 207)*

In addition, after their child was discharged, seven parents perceived themselves as having **inadequate 'medical' knowledge** and were not confident in their abilities to detect problems arising from their child's injury without medical support. Lenny's mother described her anxieties when her child was discharged. For all but one parent, these anxieties diminished over time.

*M: I was concerned about the burn and the reactions to it and not having somebody there instantly. To question err, concerned that err, you know, although you know we could ring them at any time and we did ring them about a couple of things. I was concerned when you read the discharge note, the smell, he will be sick, it's alright, but if it smells more then it might be something to bring you back straight away. I was concerned about oh if it does, how do I know? That sort of thing. (Text unit 442)*

#### 1.4 Beliefs about child's injury

Four sub-themes were identified in relation to the beliefs parents had regarding the nature and likely outcomes of their child's injury.

Regardless of the actual severity of their child's injury, all participants appeared to **appraise their child's condition as serious/injury as severe/'horrible'** at some point after their child was admitted to hospital. Most reported that they did not reach this conclusion when the accident first happened but at the initial view of the burn. Influences on these appraisals included discovering that their local hospital needed to transfer them to a specialist unit, being offered accommodation on site, and observing their child's injury. Closer observations of their



child's wounds appeared to repulse many parents and reinforced their belief that their child was seriously injured. Of the parents able to recall the percentage burns their child had received, four out of five believed the percentage to be more expansive than it actually was. Parents' perceptions of the severity and seriousness of their child's condition did not appear to be modified by their current beliefs about the outcome of the accident and they continued to appraise the original event as having presented a substantial threat to their child's well-being.

Elizabeth's mother:

*M: The doctors kept coming, taking a look and walking away. And then they did a shift change and a nurse came on, she was a paediatric nurse and she said, we'll have to take her to [burns unit]. My heart just sank, because to me that meant she was really really bad, but it was because of her age and everything...(Text unit 74)*

Karen's mother:

*M: And the other thing, err, when you took her to the bath you used to see the mess on her leg, you know, made it worse you know .*

*I: That made you feel worse, because you could actually see what was going on?*

*M: Yes, yes. (Text unit 54)*

John's father:

*F: The thing was though and another thing was the seriousness of the kids of all the people who had rooms there*

*I: In the R\*\*\*\* M\*\*\*\*. [accommodation for parents at hospital]*

*F: yeah they all seemed to be serious illness I was very worried then. (Text units 259-261)*

In addition to appraising their child's condition as serious, believing that there was a possibility that their **child could die** also proved to be a significant threat for eight families. In some cases this was prompted by the appraisal of information given to them by medical staff, but in others this seemed to be the result of the perceived severity of their child's health problems or previous medical knowledge.

Discovering from medical staff early on that their child's life could be at risk was especially shocking for Robert's parents, as in common with other parents, they had not initially appraised their child's condition as serious:

*F: When we went in first the doctor took me to one side and the first thing he said to me was he's got a 50:50 chance*

*M: And we hadn't thought of death up to that point did we.*

*F: We were gutted at that point. (Text units 530-532)*

In the absence of contradictory information, Sarah's and John's mothers reached their own conclusions:

*M: No coz they never told us anything in the hospital they weren't telling us anything even when they admitted her they were not telling us what they were going to do to her*

*I: What did you think?*

*M: I thought my baby was dying on me. (Text units 163-165)*

*M: When I first saw him I didn't think we'd be bringing him home again really it was just awful. (Text unit 332)*

While Lenny's father acknowledged that he was forming assumptions on the basis of limited knowledge, this made his appraisal of the situation no less worrying:

*F: I mean I've done, I'm not saying I'm a Doctor, I've done a lot of first aid, I know the reaction of shock and afterwards and all that and then with him obviously being very young, it's err frightening then to think a cup of tea from that, a kettle full of water could have killed him easily. (Text unit 136)*

*F: ... probably a little knowledge is dangerous and then actually I'm thinking because of the age because of the aftershock knowing what burns are or going through what burns are, then you know so all that plays a part. (Text unit 159)*

Believing that their child may die was reported by parents who had been present at the time of their child's accident as well as those who had not.

**Uncertainty regarding the course and outcome** of their child's condition appeared to remain a threat for all parents. Central to the early concerns of all the families was how badly or visibly their child might be scarred. As their child recovered, this remained a threat to a greater or lesser degree for them. Parents reported asking numerous questions of staff, with some becoming frustrated that they could not be offered a more accurate picture of the likely outcome for their child.

For those parents whose children had been burned on more visible areas (such as their necks and faces), the uncertainty appeared to be more anxiety provoking. Signs that their child was not going to be scarred badly in these areas were, therefore, particularly important to them.

Harriet's mother described her concerns about her daughter's scars:

*M: ... I mean she will always be scarred on her arm, but at least her face isn't scarred. Which is what our biggest worry was about what is her face going to look like, although they were more concerned about her arm. Her face just looked so awful. (Text unit 148)*

At the time of the interview all but one family were still involved in some kind of treatment for their child. Being unable to predict whether their child would require further hospital treatment or when the end point for their child's rehabilitation would be reached seemed to generate hope in some parents regarding the future appearance of their child's scar. Other parents remained more cautious. This depended on how the situation was appraised and continued to be appraised by individual parents. (See Section 4.3 for further discussion of hope and caution).

A related sub-theme was identified in connection with parents' difficulties in coming to terms with the uncertainty regarding their child's condition. Families expressed **fears for the future** almost exclusively surrounding the issue of their child's scars and the possibility that they could be stigmatised or become self-conscious. This was viewed as inevitable by some parents, although others remained more hopeful.

Harriet's mother expressed her concerns for her daughter when she got older but remained hopeful that this could be tackled:

*M: well my main concern is how is she going to react when she is getting older cause she will, she will be marked and when she is a teenager it will cause her problems. She is never going to be comfortable wearing little shoe string tops and stuff like that. But it is how we bring her up, to be able to deal with that. (Text unit 470)*

Predictions for when children were likely to be affected varied between families.

*M: Doesn't bother him ... I'm worried what it'll be like when he gets to mingle with other kids  
F: When he gets to school - when he has swimming lessons at school that's what I worry about. (Text units 443-444)*

Three parents observed that their children had already been exposed to experiences during which they could have felt stigmatised. Of the eight parents who expressed these fears for the future, all felt that the current age of their children protected them from the negative impact of stigma and predicted that they would experience difficulties as they got older. Karen's mother felt the future was going to be particularly difficult for her child as she had an identical twin sister:

*M: I have been thinking, yes, how she's going to be you know. Like she's going to see S\*\*\*\*\* [sister], is it going to be all right? There's not a mark on S\*\*\*\*\*. I think it's going to get harder as she grows up. I think it's easier now because she doesn't understand as much, she's only four, but when she starts school and you know things like that, I think its going to be, its going to get worse I think... (Text unit 623)*

Descriptions of threats that individual parents perceived others as presenting to their well-being are detailed in the next section.

### **Super-ordinate theme 2: Inter-personal threats to well-being**

Each parent described threats to their well-being that were associated with other people's behaviours and responses to their child's injury including their child's own response. Sub-ordinate themes fell into four main areas:

- 2.1 Perception that accident and related events have had a negative impact on child
- 2.2 Perception that accident and related events have had a negative impact on family
- 2.3 Others' responses perceived as a threat to well-being
- 2.4 Healthcare professionals perceived as failing

#### *2.1 Perception that accident and related events have had a negative impact on child*

Of most importance to parents was the impact they perceived the injury event and its consequences to have had on their child's well-being. Different indicators to parents that their child's well-being was suffering appeared to be of particular significance at certain times. Of key concern for parents when their child was first injured and in hospital were signs that their child was in **pain**.

Harriet's father stated:

*F: Your child being in pain I think that is your biggest fear I think, its hard to look at your child when they are hurt, at your kids especially when they are as young as that... (Text unit 182)*

James' mother's concerns remained despite reassurance from hospital staff:

*M: You're nervous, you just don't know how they feel. You're getting told, they're not really painful, and you think, they must be, you know. I've had a burn myself I know what it's like. (Text unit 267)*

**Changes in behaviour/ unusual' behaviour** that indicated distress or that the injury was continuing to have a negative impact on their child were also significant, both when their child was first admitted and at the time of interview. Descriptions of behaviour that parents found distressing included the nature of their child's screams when the accident occurred, seeing their child crying or upset or feeling that they were frightened regardless of whether they were in pain. Children not eating, having difficulties sleeping, experiencing nightmares and being aggressive were reported as concerns for parents when their child left hospital. Harriet's mother described

herself as being so anxious and upset in response to her child crying that she misheard what her husband had told her about his meeting with a doctor:

*M: I couldn't cope with her crying any more because every time she cried I cried so it was like um then I wished I'd stayed cause I totally misinterpreted everything he [husband] told me that the plastic surgeon had said. (Text units 204)*

Some parents drew a **comparison between their child's pre-burn and post-burn functioning** - for example, their child having to learn to walk again or needing to wear nappies during the day when they had been potty trained. Five parents described the changes they observed as particularly distressing. For John's mother, her son's visible weight loss was of concern:

*M: Doctor said it doesn't matter if it's junk (referring to food) for now just give it him to put some weight back on ...he's put it all back on but it was horrible to see him cause he wasn't the biggest baby. (Text unit 339)*

Other parents described the impact that the change in their child's temperament had had on them. For example, a previously energetic and cheerful child becoming listless and irritable.

Behavioural changes that made their child more difficult to manage, such as children making more demands of their parents or not obeying commands, were not appraised as threatening for the time period that their child was in hospital, although six parents reported difficulties managing their child's behaviour when they returned from hospital. This was attributed to their children being "spoiled" whilst in hospital. Three parents felt they were still faced with these difficulties. Beliefs about these behavioural changes post hospital and currently, differ between parents, with some describing it as problematic and others feeling that they were/are able to manage or make sense of these changes.

After discharge, six parents were concerned that their children were experiencing disturbing recollections of the accident or time in hospital and described their children being frightened of baths or hot drinks, having nightmares or being "clingy" when they had not been previously. For all but two of these parents (Sarah's and Kevin's mothers), these concerns were short lived and not present at the time of the interview.

### 2.2 Perception that accident and related events have had a negative impact on family

Parents described the difficulties of dividing their time between the injured child and the rest of their family. Parents of six of the seven families who had more than one child at home described their worries about the impact the experience had had on their other children. To a varying degree they expressed their difficulties with separation from their other children and trying to ensure their well-being whilst their sibling was in hospital. This appeared to be a threat regardless of whether they perceived their family or partners as offering support in terms of caring for the rest of their family.

*M: Yes I'd say it was they had been affected not just Karen you know. Cos, like I'd been away and coming back and F\*\*\*\* the baby she's quite close to me, err, how can I say, she's mummy's girl she doesn't do much with her father, with me, you know and she felt, I used to come home. I used to be so tired, I used to try and do the best I could with them you know, but it affected them, you know. Cos my mum used to say, err, they've been ok today, when I used to phone. They have been a bit quiet and I think it affected them as well you know.*  
(Text unit 345)

This mother was also concerned for her husband's well-being as she felt unable to offer him sufficient support.

### 2.3 Others' responses perceived as a threat to well-being

Parents readily identified the reactions of other people as unhelpful or distressing. Three related sub-themes emerged - perceptions that others were **blaming** or **evaluating** them, and **comments or actions that were unhelpful**.

Appraising family or medical professionals' reactions as **blaming** them for the accident or **evaluating** them as parents was a source of concern for several participants. John's mother recalled:

*M: M\*\*\* [ambulance driver] went up and felt the water and he come back and he made a comment I didn't quite catch what he said he just went and tutted and I thought you know what do you want me to do you know I didn't throw him in it or anything.*  
(Text unit 130)

Three parents also believed that their child may currently blame them or would blame them in the future for the experiences they had gone through. For example, Karen's mother described her daughter wanting her mother to remove her scar:

*M: Cos she does it now, when she's in one of her moods she'll say to me, take it off, pull it off (referring to scar) you know, this, you know and I say to her you can't pull it off, its there Karen and its going to be hard I think with her you know.*

*I: So how does that make you feel when she says things like that?*

*M: Yes, yes, it's really bad you think I've got this to come, got worse to come with her, you know when she's a bit older she's going to be telling us you know, its going to be worse.*

(Text units 453-455)

In preparation for this possibility of being blamed, Harriet's mother took photos of her child's injury when she first entered hospital in order that she could show her how "lucky" she had been that her injuries had not continued to look as they did when they first occurred:

*M: So when she is moaning about how hard done to she is but ... I took them in (to work) and they were quite horrified at them cause they are quite graphic really aren't they? (Text unit 357)*

Although Toby's mother sounded incredulous that she had been evaluated as a parent, this did not prevent her from acting in response to this perception:

*M: I think I was a bit worried partly because I didn't want to be away from him but even in the times where he was quite well and stable, I don't know, there was a sense, and again I know from me, oh god if I go off and the nurses will think I'm a terrible mother, even for just leaving my child (laugh). They did say, you go and do this, you go and do that, so they were very supportive and attentive. (Text unit 495)*

Although some parents endeavored to make sense of these appraisals, others avoided further exploration of the topic. When the researcher reflected on her role in the interview process after each interview, it became apparent that in discussions with all the participants there was a sense that the interviewer was perceived as part of the health service and in a position to evaluate parents. In all cases, the transcripts reflected parents' attempts to ensure that they demonstrated that they had taken appropriate action in response to the accident, and in others to indicate that they were taking their role in their child's rehabilitation seriously. This resulted in pedantic descriptions of sequences of events and unprompted, detailed explanations of particular courses of action. In one case, a parent (Sarah's mother), voiced her perception that she was being evaluated by the interviewer:

*M: I did worry when I got the thing (interview request letter) through cos I wanted to know why I was getting interviewed I thought someone was blaming me for it*

*I: Oh right*

*M: Cos I turned round to I\*\* and I said look it's finally come they want to come and question me about why she got burnt. It did scare me. (Text units 748-750)*

All parents also described **comments and reactions that were unhelpful**. These varied from people being too sympathetic, becoming upset themselves or being insensitive to parents' feelings or needs. For example, Harriet's mother recalled her feelings when she returned to work, where she had only been employed for a week before the accident:

*M: But it's quite a big place where I am working and nobody asked, nobody knew about it which was another thing*

*I: Mhmm*

*M: Once I got into work I found it really strange because if it had been where I was working previously everybody would have known about it. (Text units 335-337)*

*M: And I don't know which was worse the complete indifference because nobody knew or everybody been overly concerned for me 'cause if they had been overly concerned I would probably have spent all day skrying (sic) (crying). (Text unit 339)*

#### 2.4 Healthcare professionals perceived as failing

Eight families considered that some aspect of the service they had received from healthcare professionals was worthy of criticism and exacerbated the levels of distress they were experiencing. Parents' descriptions of professionals suggested that overall they had a mixed opinion. However, clear cut distinctions were made by seven parents between those staff whom they felt to be non-supportive or who behaved in a manner that upset them and those who they found to be helpful. Parents placed these health service staff in mutually exclusive categories, distinguishing between those who they felt were protective and those who were not. The intensity and nature of the criticism levelled at services varied. Four parents described how difficult they found it when they perceived themselves to have been "fobbed off", not listened to or felt that information they had requested had not been forthcoming. Three participants also considered that staff behaviour, such as offering parents a choice over medical decisions, was handing over too much control to parents. The manner in which they were spoken to by medical staff was also criticised by some parents.

Elizabeth's mother recalled:

*M:... and they were sort of going away and coming back and in the end they said, well we'll put some cold stuff... No one seemed to want to take control of the situation. They were all running around and didn't know what to do. It seemed like I was having to cope with me, her and take control which I wasn't particularly happy with. (Text unit 74)*



John's mother's comments reflect both her perception that some staff 'failed her' and did not listen to her but also that others were protective:

*M:... this doctor said he could take it orally and we just couldn't get through to him that he will not - I was saying he will not take this medicine orally - he will spit it out - No no he'll be fine we'll try it and I'm like no he won't and he didn't take it. I was blue in the face and L\*\*\*\*\* [Nurse] was like please listen to her he will not take the medicines he needs he will not take it ... (Text unit 217)*

### **Super-ordinate theme 3: Other threats to well-being**

The threats to parental well-being that cluster around this super-ordinate theme broadly relate to circumstances that arose in the context of their child's injury.

- 3.1 Observation of child's treatment
- 3.2 Parental separation from child
- 3.3 Safety concerns

The first two threats were predominantly mentioned by parents in reference to the time their child was still in hospital. The third, safety concerns, became more intense when their child returned home and were voiced by all parents as one of the ongoing affects of the thermal injury on family life.

#### *3.1 Observation of child's treatment*

While their child was in hospital, all parents were offered the option of being present during the various treatments that their child required. Parents recalled being warned that it would be difficult to watch and potentially distressing or uncomfortable for their child. In each family, one or both parents took responsibility for this task.

Eight parents described how difficult they found it to be present during their child's debridement, dressing changes and baths to clean out wounds whilst in hospital. Some parents attributed their distress to concerns that their child was in pain, whereas others attributed it to being unable to help their child.

Karen's mother reported:

*M: ... they used to give her something to make her feel drowsy and then she wouldn't feel as much pain going into the bath, but they had to bath her to clean it out, you know.  
C: Right.*

*M: And that was the only part I hated... (Text units 201-203)*

Some parents decided they could not be present at this time and readily handed the task over to other family members or their partners, whereas others felt it was important that they remained with their child at this time despite their own distress.

In general, parents did not feel that observation of treatment at post-discharge visits to the hospital was distressing. However, three expressed their relief that they would no longer have to attend scar management clinics indicating an endpoint to the experience.

### *3.2 Parental separation from child*

Being separated from their child for even a short period of time was something that most parents interviewed sought to limit. This threat seemed to be related specifically to the thermal injury experience, as all the injured children except one were being cared for by nurseries or child minders for at least part of the day prior to the accident.

Nine of the parents who remained with their children during their time in hospital described their difficulties at being separated from their children. Some considered that it was the age of their child that made this particularly difficult. For others it was important that they were not viewed as neglecting their child. Toby's mother recalled feeling that despite encouragement from staff, she found it difficult to be separated from her child:

*M: ...I didn't leave him literally for a second and they [hospital staff] were really good, encouraged you to stay. But things like, just going to the loo, I would panic and going to the loo think, oh my god I can't be away from him for long. But they were really good, they didn't make you feel that you should or you shouldn't be there and they were supportive it was just (pause). Things like going to have a shower, didn't want to leave him. (Text unit 199)*

### *3.3 Safety concerns*

All the participants interviewed felt that their concerns about being able to make an environment safe had increased since their child's accident. All mentioned a heightened awareness of danger, with one father feeling that it had confirmed his pre-accident concerns about the need to be extremely vigilant around children.

The extent to which safety concerns impacted on family life varied. For half the parents this involved taking specific safety measures that ensured a similar accident would not recur, such as

ensuring that hot drinks were always placed in the centre of tables. One parent, Harriet's mother, now avoided drinking them altogether:

*M: ... [talking about elder sibling of injured child] don't go near that you'll get burnt but that's just cause he's listening to us and we are always saying to him do you want to end up back in hospital, don't be playing with that cause it is too hot. I mean it has probably affected us more than it has affected them cause I mean I am paranoid about coffee and I very rarely drink coffee at home now. (Text unit 305)*

Three parents indicated that they had more generalised fears for their children's safety since the accident and were concerned about leaving them for even a short period in a room on their own. For Sarah's mother this meant that she was having difficulties assuring herself that her children were safe unless she was with them:

*M: I don't know ... I don't like any of them being out of my sight and I hardly ever let these two play out [referring to injured child's siblings] now it's not very often they play out. (Text unit 358)*

*M: No I want to stay with the baby cos in the back of my mind I know it's stupid but I feel if I leave them then they're going to hurt themselves cos I blame myself for it. (Text unit 418)*

#### **Super-ordinate theme 4: Coping with threats to well-being**

Examination of the strategies used by parents to cope and the links between these and particular threats to well-being suggests a complex relationship. The summaries presented in Tables 5 a, b and c indicate that parents engage in a number of different strategies to cope with or manage threats presented to them by their own appraisal of the accident as well as those threats presented by other people.

Themes relating to coping strategies cluster around seven sub-ordinate themes:

- 4.1 Distancing self from emotions generated by accident and its consequences
- 4.2 Overcoming difficulties/regaining control
- 4.3 Maintenance of hope
- 4.4 Managing blame/guilt
- 4.5 Making sense of and justifying own and others' reactions
- 4.6 Systemic management strategies
- 4.7 Help and support from others

#### 4.1 *Distancing self from accident and its consequences*

Parents offered stories suggesting that at times they used a number of strategies to distance themselves from the events surrounding the accident to avoid being overwhelmed by thoughts and feelings that were unmanageable. A number of sub-themes were identified around this subordinate theme.

A common strategy identified when their child was first injured and still in hospital was to attempt to **cut off from emotions**, with some parents describing it as functioning on ‘**automatic-pilot**’. This was shown in Harriet’s mother’s account:

*M: You are just on automatic pilot aren't you you just go through the emotions you do what has got to be done. (Text unit 328)*

Lenny’s father described his approach to coping whilst his child was in hospital:

*F: Getting there, being there as long as you can, and then the in-between times being busy. (Text unit 213) ... I just don't want to know, want everyone to just get out the way, I want to just get on and do what I want to. (Text unit 214)*

For three parents this meant that during their interview they had difficulties describing the coping strategies they used early on. Like others, John’s parents’ narratives did not reveal particular strategies but suggested that they had attempted to **cut off from emotions**:

*I: What do you think about how you coped during that period?  
M and F: Had to. (Text units 483-484)*

*F: Yeah - it's not easy and the thing is you've got keep going. (Text unit 492)*

A closely related reaction to the initial shock of their child being burned was **disbelief** regarding the seriousness of the event. Seven parents described gradually realising the significance of their child’s injury:

*M: ...and it just wasn't registering you know the seriousness and then I thought they put some cream on and some bandages and bring him home and then they said they'd take us over to Alder Hey and I'm like Why? You know. Why are you doing that? And he just wasn't so we didn't and then we just had to keep waiting and waiting. (Text unit 81)*

For a short period of time this protective parental strategy seemed to enable them to cope with the initial shock of their child’s injury and employ appropriate coping strategies.

In recalling experiences and discussing the impact that their child's burn currently had on them, parents appeared to use a number of strategies to distance themselves from their recollections. Seven parents used **humour/euphemisms** or **avoided emotive language** when recalling aspects of their own and their child's reaction to the event. For example, although Harriet's mother acknowledged that her child's life could be at risk, her comments suggest that she tried not to consider this as a serious possibility:

*M: ... we first went in they said right the next 48 hours are really ... critical that makes it sound like she was at death's door but you know your body can go into shock and you can get ... they say it was bad ... like the temperature kept going up. (Text unit 312)*

John's mother appeared unable to refer directly to the possibility that her child could have died, although her comments suggest that she had considered this to have been a possibility:

*M: When I first saw him I didn't think we'd be bringing him home again really it was just awful.. (Text unit 332)*

Finally, a strategy used by families to minimise their beliefs that the injury had had a negative impact on their child was to **explain away the impact of injury on their child**. For example, John's parents felt that their child's age protected him from suffering some of the negative impact of the injury:

*I: How do you think being burned has affected John. Do you think it's affected him at all?  
M: Not at all (said with certainty).... Not now.  
F: I think he was too young for it to affect him but it might do when he gets older and starts mixing with other kids it might do. (Text units 368-370)*

For Sarah's mother it also seemed important to believe that her child has suffered no adverse effects:

*I: Right umm...so in what way do you think the burn injury has affected Sarah?  
M: It hasn't affected her at all (laughs a bit)  
I: It hasn't affected her at all?  
M: If anything she's gone wilder. (Text units 317-320)*

In attempting to explain the impact of injury on their child, parents also highlighted evidence that their child was coping well or that behaviour post-injury was not particularly unusual. One

method of doing this appeared to be **normalising the child's reaction**. For example, Harriet's parents discounted any suggestion that their child had suffered any lasting effects from her injury:

*M: My mum says she has gone more moody, like more clingy whingey but I don't know cos she was only young anyway and I don't know what she would have reached that stage anyway, cos she has always been a thumb sucker she's always been one for her dolls and her teddies to cuddle. She takes her blanket to bed with her now which she wasn't doing then, but so did my sister at that age...(Text unit 268) ....but I mean my sister used to suck her thumb and used to have a piece of cloth and my niece did as well, and she always had to have flanneling she liked the feel of them. So it is just something people do... (Text units 272)*

Seven parents described actively **avoiding accident reminders** or believed discussions of the accident served no purpose and could be detrimental. Sarah's mother felt unable to use the fire below the mantelpiece on which the cup of coffee that injured her child had been placed, whereas John's mother found she could not have a bath (in which her child was scalded) in the house where the accident had happened:

*M: ... I wouldn't go back in the bath there I came here to have a shower for weeks and weeks afterwards. I used to get the bus every morning to come and use the bathroom upstairs [at parent's home]. I wouldn't entertain anything to do with the bathroom at all if I was desperate to go to the toilet I would but that was it. (Text unit 359)*

One parent said she would not to return to her local hospital, preferring to make the longer trip to the regional burns unit and another felt that she had been unable to "feel settled" in the flat where the accident happened and had moved.

For five of these parents reminders remained such a threat that discussions were avoided. For two parents the interview was the first time they had discussed the accident and post accident events.

#### 4.2 Overcoming difficulties/regaining control

Parents used a number of strategies in order to combat the emotional and practical difficulties experienced. These strategies represented efforts to regain control over situations which were beyond their experience.

The capacity displayed by parents to address the requirements of the crisis that arose when their child had just been injured, is represented in the sub-theme **using practical coping**. Toby's mother's reflections are representative of parents' efforts to do this:

*M: I was sort of in panic mode, it was like you had two different things going on. There was part of me that was just knowing that I had to do things, I had to call the ambulance, make sure they got here, make sure Toby was OK. But at the same time I couldn't breathe properly... (Text unit 128)*

A related sub-theme was parents finding a **belief in their own resources or developing strengths** to manage their emotional response to painful experiences, such as being with their child during dressing changes or coping with the overall experience of their child being hospitalised. Six parents described this response, including Lenny's mother who also expressed her surprise at her own resources:

*M: Well they'd have given him drugs to calm him, he still sensed so much of it anyway, the pain and that, the bathing and that and it was hard, I was fighting back the tears at the time. That strength you know to keep going, being able to talk to him and smile at him, you know that helped me and the fact that I could do it. (Text unit 246)*

One of the consequences for parents of developing such beliefs was being able to overcome their ideas about being unable to help their child or doubting their care abilities (see sub-ordinate theme 1.3). Combating these views also evidenced in some parents a growing belief that they were in a position to **monitor the child's medical care/question professionals** and protect them from care that they perceived to be inappropriate.

*M: I mean they were very good, they were excellent there were just a couple of them that were not really ... I mean that day that that K\*\*\* come in John had seven different syringes they had been giving them through his drip and I was trying to say they weren't giving them orally they were giving them down his drip she wouldn't have it, she threw them straight down him and I ended up snatching them off her ... (Text unit 234)*

*M: I said I'll give him it and I swore blue that day I'd pounce across the bed and I felt like if John wasn't in front of me now I'd bounce at you but she... (Text unit 236)*

Although this seems to represent a strategy for regaining control it was not always perceived as such by parents. Some viewed themselves as 'battling' against healthcare professionals or became frustrated that their questions were not being answered. Nonetheless, five parents advocated asking questions as a way of coping for parents of burn's victims.

James's mother stated:

*M: Yes, if you're not a pushy type of person, ask questions, don't just sit there and put up with what they tell you. Ask questions, make sure you get things done. Make sure you know what your baby needs, because at the end of the day they know burns patients but they don't know your child, and every child is different. There's certain care that your child needs that only you can give and only you know what they need that you can get from somewhere else. So you have to sort of guide them, he/she needs this. (Text unit 488)*

A further sub-theme related to parents regaining control was their **beliefs about ensuring their child's safety**. Although all parents had mentioned their heightened concerns about their child's safety, their confidence in the steps they had taken to ensure safety varied (see sub-ordinate theme 3.4). This seemed to depend on whether parents maintained a general view that most environments were hazardous for young children or felt that particular dangers (which could be guarded against) were present.

These contrasting stances are illustrated in the views of Lenny's and Toby's parents:

*F: You know and every time because, you think all these things happen you know, and D\*\*\*\* [partner] within touching distance of him and that happens, you know, I suppose we're probably even more protective than we naturally would be. (Text unit 515)*

*M: Even when he came home and still had the bandage on he was still ...we'd always been careful anyway it just happened. But we're still really careful in the kitchen, especially leaning against something or up there somewhere so that he can't go anywhere near it. (Text unit 277)*

#### 4.3 Hope maintenance strategies

Strategies which formed the cornerstone of parents' management of threats to their well-being were those that enabled them to continue to be hopeful about the outcome of the burn injury for their child. Different hope maintenance strategies appeared to dominate at different points in the process of parents' adjustment to their child's injury.

Being able to begin **gaining hope from healing signs/child's behaviour** appeared to represent a significant turning point for all the participants away from appraising their child's condition as **serious/injury as severe/'horrible'** (see sub-ordinate theme 1.4). Parents invariably described these changes as sudden or dramatic with some considering the recovery as 'miraculous'.



Harriet's mother recalled:

*M: The first few days it gets progressively worse and worse and worse and then all of a sudden on the Friday the scabs started coming off and it really seemed to come on in leaps and bounds didn't it? (Text unit 217)*

Eight parents felt that the improvements that they could observe in the appearance of their child's injuries were important to them. Changes in the appearance of their child's scar, however small, also represented a source of hope for parents.

Karen's mother:

*M: (pause) I'd say every day seeing Karen getting better and you know there's a hope you know you're going to go home from there. (Text unit 615)*

Sarah's mother:

*M: When she came home and I was putting the cream on her all the time it faded cos it was red all the time and then every time I was putting the cream on it was going pinky*

*I: Right*

*M: So it looked a lot better. (Text units 303-305)*

These changes continued to represent a source of hope over time. Lenny's parents felt that seeing improvements and discussing these changes with staff at follow-up hospital visits helped them to cope:

*M: Seeing the results as well.*

*F: That's right you've seen the improvement and you're never a long way away from the next visit. (Text units 564-565)*

All parents described **gaining hope from their child's "strength"** or behaviour that suggested that they were being brave or 'spirited' despite the distressing circumstances. Descriptions of behaviour that parents perceived as indicating that their child was coping were prominent in parents' narratives. Hope gained through a belief that their child was coping was evident in parents' reports from the time the accident occurred to the time of the interview.

Sarah's mother recalled her child's behaviour in casualty, noting that to her it indicated that her child was not in too much pain:

*M:... she was just brilliant cos she helped us get through it actually with her cos I think if she'd just laid there I think we would have been worse but with her being playing all the time I don't think she was in that much pain - well that was the way I got through it. (small laugh)*  
(Text unit 388)

Elizabeth's mother felt that her child's behaviour had significantly influenced her own well-being:

*I: What do you think has been most helpful to you since you have been home?*

*M: Probably the way she has recovered from it, it does help you get on with it ...*

(Text units 236-237)

Similarly, behaviour changes that indicated their child was 'back to themselves' were found to be encouraging by participants, both while their child was in hospital and in describing their child's current behaviour. This is demonstrated in Lenny's parents' description about what currently helps them cope:

*M: Also seeing him, your child playing*

*F: He's very happy*

*M: Yes*

*F: He's very happy in himself*

*M: Seeing him like that, I haven't damaged him too much is the first, his personality and that.*

*That he wasn't you know, I was worried that he would be having nightmares about it and things like that. He's never been affected in that way. (Text units 567-571)*

Six parents confidently maintained **beliefs in recovery** at various times for their child.

Toby's father:

*F: It was a bit of a shock for me, I thought he's going to have a bit of a temperature because skin's been left over all that time but I thought being on the drip it would be a bit more serious. But I wasn't that worried because he is just so ridiculously healthy anyway that I didn't think he would be suffering for long. (Text unit 215)*

Robert's mother described this strategy as her method for challenging her thoughts that her child may die. Sarah's mother described her prediction that her child's scar would continue to improve and would eventually heal.

In contrast with these more idealised views of the future, some parents were hopeful but had a degree of **caution**. These ideas appeared to help parents to maintain a balance between remaining hopeful while guarding against possible disappointment. These strategies predominated when parents discussed their current appraisals of their child's recovery status.

Lenny's father described his assessment of their current situation:

*F: It's already improved more than you dare hope, so every improvement from now on is a bonus. (Text unit 606). And I, I feel now it isn't such a burden for him to live with, if it didn't improve any more. (Text unit 608)*

Harriet's mother described two conflicting strategies, remaining cautious about future changes, but hoping that the appearance of her child's scar would change:

*M: I don't know, maybe it was always at the back of my mind thinking that there is going to be some wonder miracle thing that was going to happen and she was going to walk away from this without any marks at all cause you don't like to see, think of your kids been scarred ...but if she is not, she is always going to have a mark. (Text unit 431)*

*I: So you were saying that thinking about there not being a miracle cure and coming to the end of the pressure garment thing, is that something that has made you feel a bit differently?  
M: Just ... don't know ... it is hard to say I just keep thinking at the back of my mind - that is as good as it is going to get.. (Text units 434–435) ... even now you can see the difference in the scarring from what it was a month ago but I think cause ... it is always going to be there, I can't explain it, it is just there at the back of my mind I don't know whether it is a disappointment or not but that is as far as it is going to go. It won't be because it will get a bit better. (Text unit 437)*

The most commonly used strategy for maintaining hope was **social comparison**. This strategy was used at some point by nine of the participants and was apparent in their recollection of how they coped whilst their children were in hospital and in the accounts they offered at the time of the interview. Parents' narratives indicated that the strategy they used was one of comparison: comparing their child's condition with those who they felt to have worse illnesses (such as leukemia); comparing their situation to families whose children had experienced similar injuries but had recovered; comparing their child's condition to those who had worse burns but who they also perceived as having recovered well and comparing their own situation with a projected 'worst case scenario'. As demonstrated by Lenny's and John's mothers, these strategies were sometimes used in combination:

*M: (interrupting partner) Yes, at the end of the day, you come back to the same thing as I said before. But as you can see, you're just so thankful that it could have been so much worse and you know. Compared to some diseases that some kiddies get that happen, you know, heart disease, I mean it's nothing compared to that. (Text unit 605)*

*M: But you see like a little boy in with a mask on his face it sounds awful but you can hide his feet so if it had to happen if there's someone up there saying it's going to happen I 'm glad it was his feet.. you can always put them away. (Text unit 308)*

In addition, five parents noted that it was helpful having either other parents in the burns unit or non-family members comment on their child's improvement or provide reassurance that their own child had looked worse before they started to look better.

#### 4.4 Managing blame/guilt

All participants discussed the issue of feeling blamed and seven of the interviewees described feeling guilty that their child had been injured. Over time, parents appeared to have developed a number of strategies to manage these perceptions or reduce the intensity of these feelings. For most parents these strategies involved a combination of attributing their child's accident to a unique set of circumstances and concluding, with the support of family members, that no one was to blame. The latter strategy appeared to allow blame for the injury to be shared with others or 'diluted'.

**Attributing the accident to a unique set of circumstances** was reflected in the explanations offered by parents to the interviewer when asked to describe how the accident happened. As discussed previously, parents' explanations suggested that they were keen to prove to the researcher that they would have had difficulties predicting the accident or that the circumstances in which it occurred were unusual (see sub-ordinate theme 2.3). This is demonstrated clearly in Harriet's mother's account:

*M: Um yeah I was making a cup of coffee, went into the fridge to get milk and she just reached up and pulled it as my back was turned looking for the milk in the fridge, just seen her pull it over herself,*

*I: Mhmm*

*M: Just all went down her face,*

*I: It was above her was it?*

*M: Yeah, I mean the week before she would not have been able to reach. She just managed to get her fingers to it. (Text units 117-121)*

Deciding there was **no one to blame/concluding the event was an accident**, seemed to result from discussions between mothers and fathers and was also evident in the conversations between parents during the interviews that involved both parents. This is demonstrated in Robert's mother's account and the discussion she had with her husband during the interview:

*M: We were feeling so out of it completely that you didn't say, something like this, oh it was your fault. That never came into the question, we realised, obviously that it was an accident but I don't think either of us ever blamed each other - I didn't say oh you put the bath on. And we never blamed Joe who had left the door [to the bathroom] open because it was just one of those things. It happened, it was an accident and yes, things could have been done differently but it happened and there was no way we could change that so we never blamed each other... (Text unit 120)*

*M: It was the only thing you could do really. Because there has never really been any question I think whether some people do blame, we've never done that really have we?*

*F: Not even with Joe. You couldn't blame him. (Text units 451-452)*

Reaching a conclusion regarding blame appeared to be a long-term process. In five parents' reports it became clear that this process had been thwarted (at least initially) due to the position adopted by one parent or both parents. This seemed to occur when either one parent blamed the other or another family member or when discussions of blame were avoided. Harriet's mother stated that not discussing the injury ensured that blame could not be assigned:

*M: Yeah to each other. Cause I mean there's no, there is no point in discussing it cos then it would get down to apportioning blame.*

*I: And do you think that is something that could have happened if you had discussed it?*

*M: I don't know ... I don't think we would have done but we have made sure we haven't.*

*(Text units 453-455)*

Some activities described by parents were appraised as, or could be considered as, **making up for the accident to their child**. This is demonstrated in the reports of John's, Lenny's, Karen's and Kevin's mothers:

*M: If you sit back and, realise what has happened to him you know if you shout at him for doing something it's like you shouldn't be shouting at him because he might not be here...*

*(Text unit 500)*

*M: ... that to me is the least I can do for him is to follow all the treatment he's been given, much assistance, give the healing as much assistance as I can to make it minimal and make sure any scarring doesn't get worse. Because I owe it to him, you know, well not owe it to him [said as a question to self] I mean that's just the way you should be you know as far as I am concerned. You only want to give, put everything into there and then you can only do your best...*

*F: Yes, well that's right there's nothing that's too much effort to promote the best recovery...*

*(Text units 300-301)*

*M: ... When they were playing with their toys, you'll sit with them and watch them and you get more. You know, you forget about the cleaning and more, you know, try and do cleaning at night when they're asleep. Try and give more attention to them in the day you know.*

*(Text unit 502)*

*M: They said, do you want to go out? [referring to nursing staff] No I'm staying with him because I felt like I had let him down earlier that day, and I thought, well I'm not going to leave him again now. So I stayed with him.... (Text unit 99) ...But I couldn't leave him, I couldn't kiss him goodnight and say, see you, I'll be back tomorrow, because I felt like I owed him for me to be there with him. (Text unit 143)*

It seems possible that these activities were ways of reducing parents' feelings of guilt about their child's accident. Some parents considered their behaviour to be an understandable response to their child having been ill. On the other hand, others suggested that they felt it was important not to change their approach to parenting and to ensure that their home situation returned to normality as soon as possible.

#### 4.5 Making sense of and justifying own reactions

The accounts that parents offered of both their own emotional responses and difficulties in coping were often alongside explanations or justifications of their own reactions

Three strategies seemed to be used by parents in their attempts to find meaning in their own reaction to the injury event and after-care. **Justifying** their behaviour, **normalising their own reactions** and **normalising the event** emerged as sub-themes from the parents' accounts.

During the interview five parents reported finding reassurance from the fact that many other children had also been accidentally burned. **Normalising the event** and its consequences appeared to represent a strategy for managing guilt and was appraised by Elizabeth's and Toby's mothers as such:

*M. Yes, and also friends at work who have got children all of them have had different kinds of accidents, including burns and scalds. So knowing that it wasn't something (pause) part of it knowing that it wasn't your fault, that accidents happen... (Text unit 606)*

*M:...You speak to so many people that you wouldn't think it would happen to and it does. Nurses come up and say, don't worry she'll be alright, my little boy did this, my little girl pulled the iron over. You're a nurse, how could you let it happen, but it's just part of life, accidents happen and you can't avoid every accident (Text unit 209). ...I suppose just, like I said before, accepting that you are not to blame, it was a pure and simple accident. Once you start to accept that it is a lot easier. (Text unit 241)*

Karen's mother's comment, made in response to her perception that her husband was blaming her for having been upstairs at the time of the accident, also suggested that she was using a similar strategy:

*M: Yes, with me and then I said well, you know, things happen. It's just you can't look after them 24 hours a day. You can't sit in a room and just not move you know. (Text unit 178)*

Parent's attempts to make sense of their own behaviour appeared to be an ongoing process. **Justifying** their current approaches to parenting was evident in the reports of seven parents. In five cases these reports included explanations of why they felt it was important not to 'overprotect' their children and to provide their child with clear boundaries for their behaviour. The other two parents justified changes in their parenting approaches such as providing looser boundaries in discipline for their child.

Parents' reflections on their own behaviour also included attempts to **normalise their own reactions** to threats and thus minimise the significance of some of their actions or apparent changes in their beliefs. This strategy was apparent in the stories of six parents. Harriet's mother demonstrates this when discussing why she now avoided drinking coffee (the cause of her child's injury) at home:

*M: I mean it you got to the point where I didn't drink that much anyway cause with having twins you make a cup of coffee and you are lucky if you get to have another look at it again, but ... (Text unit 307)*

#### 4.6 Systemic management strategies

The impact of threats or perceived threats on individuals were appraised by parents as having an affect on the family system. Nine families discussed the way in which roles were allocated or taken up in relation to coping with the emotional sequelae of the accident event and after-care in addition to specific tasks associated with caring for the injured child. The accounts of six families seemed to reflect an **allocation of roles** by gender, with fathers considered as being 'strong', 'silent', and 'non-emotional'. These roles appeared to be reinforced not just by womens' appraisals of their partners' response, but also by mothers' appraisal of their own coping style and their partners' view of how they coped or might have coped. The contrasting beliefs of parents regarding coping are reflected in the following excerpts from Toby's and Lenny's parents' stories.

Toby's parents:

*F: J\*\*\* (partner) tends to think things in a darker light than I do. You do worry and you were quite upset I remember when we went into the ambulance? (Text unit 181) ... I'm glad that it was me that was in the kitchen not you, because I think that you would have been totally a whole lot worse then... (Text unit 455)*

*M: You don't seem to be any different still laid back (laugh)... I just imagine the very worst is happening... I'm just thinking of the most horrendously strange and bizarre things that could happen and I'm always aware of that. (Text unit 477)*

Lenny's parents:

*F: I think it was just a matter of, I was being a bloke, just trying to do practical things rather than emotional things. Yes, it was like, get things sorted. (Text unit 499)*

*M: I think we're quite a bit different in that way, I need to talk a lot, D\*\*\*\*\* doesn't.*

*F: I don't, I'm not really interested in anybody at all, no family, no nothing...*

*(Text units 215-216)*

The **allocation of roles** was also appraised as a useful coping strategy in response to the demands of hospital treatment and after-care by some parents. John's mother found it helpful that her partner was always present for her child's dressing changes and her partner felt it was important that he did this:

*M: ... you went in every time for the treatment every time [said to partner] I couldn't face going in even when he was getting better ...*

*F: I was working but I'd been having time off work every bandage change.*

*(Text units 246-247)*

*F: I don't think you'd have been able to do it. [said to partner] (Text unit 255)*

Karen's mother welcomed her husband being assertive with the doctors at the local hospital, resulting in her child being transferred to the regional burns unit for more specialist care:

*M: ... He said, you're not keeping her here today I'll take her in the car, you know, he got really aggressive with them. The doctor said, well I'll have a look first, well she's not staying here today he said. (Text unit 195)*

One of the consequences of **allocation of roles** was the belief by one parent of the need to be strong on behalf of their partner and/or children. **Being strong for their child or partner** was positively appraised by some parents who indicated that it helped them to cope. The majority of the parents interviewed appraised their initial emotions as paralysing. They described these feelings subsiding as they felt it was necessary to 'be strong' for their children. This seemed to be a way for parents to regain control of parenting and reduce the sense of helplessness they initially felt. Lenny's mother's comments reflected this viewpoint:

*M: I think it was myself you know, coming to terms with myself, and realise what made me feel better was knowing that I'd got to pull myself together couldn't be a hysterical wreck. Because there was a child there who needed the strength of like his mother there with him, he needed, he didn't need somebody you know, that was crying every two*



*minutes and that...* (Text unit 240)

For some parents, such as Lenny's mother, this was accompanied by a **belief in their own resources or developing strengths** (see sub-ordinate theme 4.2), or a belief that their role was an important part of supporting their family. For example, Toby's father felt that his own coping style helped his partner cope:

*F. ... I feel like (pause) I'm just naturally optimistic anyway which helps and I sort of put that through for J\*\*\*'s [partner] sake something told me really. Just be optimistic for everybody...which does help.* (Text unit 223)

For others, both role allocation and the necessity to 'be strong' was less welcome and was viewed as an inevitable consequence of either their own or their partners pre-existing coping styles. Of the parents who felt their only option was to adopt a 'coping role', Sarah's and Kevin's mothers and John's father appraised the experience negatively.

Although John's father had felt able to manage the distress he felt when observing his son's treatment whilst in hospital, at the time of the interview he reported nightmares about witnessing his child's treatment. Kevin's mother felt she had no choice but to be present during all her child's treatment as her partner found it too distressing to observe:

*M. At the time I felt angry, because I didn't particularly want to, I don't know, I suppose it's like everything else, you always think like (pause) its always left down to the mum... Because of my husband's past, he's been through a lot in his past, to actually see Kevin in that much pain would have probably opened a lot of old wounds and destroyed him. (Text unit 143) He just doesn't deal with suffering very well. And I can understand that but I think that's probably why I ended up feeling so isolated...* (Text unit 326)

Appraisals of ongoing and past threats to parental and family well-being also seemed to be managed by parents adopting **polarised views** of the story of their experiences. The result of this polarisation was either for one parent to minimise the threats indicated by their partner's account or to emphasise the impact that a threat had had on themselves, their child or family. In the former case, the effect of this strategy appeared to be to keep the threat at a manageable level for the family. Lenny's parents showed this in their discussions about the future:

*M: Err, obviously that depends on, how much is going to, how much scarring he's going to be left with, you know how much and how also obviously you've no idea of how, like you say he is going to grow and how much will have an impact on the scar. But you do sort of have worries that*

*F: (interrupting) No, I don't have worries*

*M: Don't you?*

*F: I'm optimistic. (Text units 599-602)*

In the latter case the strategy seemed to serve the function of ensuring that the family remained cautious or kept the memory of particular threats 'alive'. This was demonstrated in Robert's parents' reflections:

*M: It's one of the big worries that's hovering... The fact that he was going to be scarred came into play and it was like, how bad was it going to be, was it going to affect him? Children are evil and he might get teased at the school. I don't think it's really going to affect him going to school or anything.*

*F: But there was that little girl last year wasn't it. She noticed him and she wouldn't play with him. (Text units 230-231)*

#### 4.7 Help and support from others

In contrast to parents' descriptions of unwelcome role allocation, all parents suggested that being able to **share the care or let others parent** was helpful or allowed them respite from **being strong for their child or partner**. Parents' beliefs about the consequences of handing over control of care to medical staff or other family members appeared to vary. Allowing others to take over was most commonly adopted as a coping strategy when the burn injury first occurred. Five parents described feeling that they had temporarily 'reached their coping limit'. This was demonstrated by Harriet's mother who recalled it being necessary for her husband to take over when talking to doctors about her daughter's prognosis:

*M: ...and then when the plastic surgeon came to see her the first time on the Monday you stayed with her then and I went out cause by that time I was just I just couldn't cope with anymore so. (Text unit 202)*

However, as parents began to adopt other coping strategies, handing over control to other people was appraised by some parents as a less useful coping strategy. Over time, parents who believed that handing over care to family members was an option, even if they did not take up the opportunity, appeared to cope better than those who did not.

The **support of family and friends** was cited by all participants as helpful. Only five participants specifically referred to their partners as supportive. Eight parents found the support they received from family and friends to be useful. Both practical help and ongoing emotional support was valued.

Harriet's mother noted:

*M: I mean one of my friends used to wash her hair cos when she had her bandages on she couldn't have a bath so she couldn't get her hair washed so we used to wash her hair of a weekend and stuff like that really I mean that is where you need the help. (Text unit 443)*

John's mother recalled:

*M: My dad has probably been the stronger one out of all of us when his feet were like that at first it hurt but me dad persevered which we were absolutely gob smacked about so my dad does the cream and like he won't watch Casualty or anything and then he does that. (Text unit 472)*

Lenny's mother described what she had found helpful:

*M: (pause) err, I think people being around, you know, err it was always important when D\*\*\*\* [husband] got there I'd wait for that. It's important that other members of my family came as well ...I needed to talk so much, you know. Sometimes that's part of your process of healing, if you like, talking going over it and doing I think it feels necessary you know to get over it. (Text unit 209)*

For five parents, knowing that their other children were being supported by other family members or their partner alleviated some concerns about the negative impact of the event on the family.

Support from people less well known to the family was also deemed to be important. All except two parents found the support offered by other parents on the ward and at clinic visits to be useful. Expressions of concern or encouraging comments about the status of their child's recovery were appreciated. Four parents also described the support they received in facilitating their child's return to nursery or their child minder as important.

Aspects of **support from health care professionals** were appraised differently by different parents. Six parents valued being **given information by staff** both in response to their questions and spontaneously. These parents appeared to value attempts to reduce their levels of uncertainty even if some information came as a shock.

Harriet's mother felt that information had been key but notes that she had had difficulty taking it in:

*M:... they have a pretty good ball park idea of how bad it is going to be. They won't tell you it is not going to be bad if it is going to be, they won't give you false hope .. but I think the thing is you have to listen to them... cause we didn't did we? I mean they said oh no her face is, will*

*be fine, don't worry about her face, her face will be fine and we we're like there is no way.*  
(Text unit 502)

Lenny's parents' accounts indicated their views on helpful staff behaviour:

*F: Yes, he was keeping you in touch with reality, stopping your mind running riot. Which tends to and very often in a lot of whenever you go to hospitals and I've had a lot of and I'm the kind of person well, lets know what the score is, and so many times you know you've said you go visiting people don't you and they waltz you in and they come in with machinery or with tablets and there is no explanation and that was everything that he was doing or involved in was explained. Right, well I'm going to do this and I'm doing this because of, you know and that was good.* (Text unit 168)

*M: (long pause) I think I wanted the most, I think was information, what to expect, you needed to be*

*F: (interrupting) reassured*

*M: reassured, yes.* (Text units 550-552)

Interestingly, three of these parents also reported feeling that some staff may have appropriately withheld information from them in the process of reassuring them.

Staff behaviour or comments that parents believed to be reinforcing of their own care skills or actions was highlighted by seven parents. Reassuring parents that it was OK to take a break, taking parental concerns seriously and not intruding on the care that parents were providing, were cited as examples. Two parents seemed to find the comments staff made specifically about their role in response to their child's injury and treatment particularly reassuring:

*M:.. she said to us that actually I'll honest with you, it made me quite proud of myself actually, whatever E\*\*\*\* did at the time she said, burns carry on burning for 20 minutes afterwards and she said whatever E\*\*\*\*\* did she stopped that burning - she acted quick enough to stop it - I mean I didn't think I did at the time but I must have...(Text unit 180)*

## **Overview of links between threats, strategies used to cope, and adjustment over time**

### *Threats to parental well-being and corresponding coping strategies*

Parents' attempts to manage threats to their well-being resulted in a number of coping strategies being adopted. Some strategies appeared to be adopted in relation to a number of threats. On the left-hand side of Tables 5a, b and c, those sub-ordinate themes and sub-themes are listed that could be grouped together under the three super-ordinate headings. On the right-hand side, corresponding strategies used by participants in order to cope with these threats are listed as they cluster around specific sub-themes. The sub-ordinate theme numbers under which these sub-themes can be found are listed on the far right. This is not intended to suggest a one to one

relationship between threats and coping strategies, nor to suggest that a uni-directional, linear relationship exists, but is offered as a framework within which to link elements of the stories presented by parents. It does not offer a picture of the variation in parental beliefs regarding what was, or is, threatening to their well-being and/or what they perceived as helping or hindering their adjustment over time.

**Table 5a** -Threats to parental well-being and corresponding coping strategies. Super-ordinate theme 1: Intra-personal threats to well-being

<b>1.Intra-personal threats to well-being</b>	<b>Coping with threats to well-being</b>	
1.1 Emotional responses Struggling with shock/panic/upset Distressing recollections/image	Cutting-off from emotions/auto-pilot	4.1
	Using humour/euphemisms/avoiding emotive language	4.1
	Using practical coping	4.2
	Avoiding accident reminders	4.2
	Normalising own reactions	4.5
	Justifying own reactions	4.5
	Allocation of roles	4.6
	Share the care/let others parent	4.6
	<i>Help and support from others :-</i>	4.7
	Family and friends supportive	
	1.2 Self blame/guilt	Explaining away impact on child
<i>Managing blame by :-</i>		4.4
No one to blame/concluding event was an accident		
Avoiding discussions re blame		
Attributing event to unique set of circumstances		
Making up for accident to child		4.4
	Normalising event circumstances	4.5
1.3 Unable to help / doubting care skills Helplessness/parenting skills challenged Perceiving 'medical' knowledge to be inadequate	Monitoring child's care/question professionals	4.2
	Beliefs re own resources/ strengths	4.2
	Allocation of roles	4.6
	Parental separation from child (limited)*	
	Share the care/let others parent	4.6
	Staff supportive	4.7
1.4 Beliefs about child's injury Appraising child's condition as serious/injury as severe/ 'horrible' Child could die Uncertainty re course and outcome Fears for future	Cutting-off from emotions/auto-pilot	4.1
	Disbelief	4.1
	Using humour/euphemisms/avoiding emotive language	4.1
	Beliefs in recovery	4.3
	Gaining strength from "child's strength" or behaviour changes	4.3
	Gaining strength from healing signs	4.3
	Caution	4.3
	Polarised views of story	4.6

\* Coping strategies that was also identified as threat

**Table 5b** -Threats to parental well-being and corresponding coping strategies. Super-ordinate theme 2: Inter-personal threats to well-being

<b>2.Inter-personal threats to well-being</b>	<b>Coping with threats to well-being</b>	
2.1 Perception that accident and related events have had a negative impact on child  Pain Changes in behaviour/behaviour unusual Comparisons between child's pre and post burn functioning	Explaining away impact on child	4.1
	Normalising child's reactions	4.1
	Being strong for child or partner	4.2
	Monitoring child's care/question professionals	4.2
	Gaining strength from "child's strength" or behaviour changes	4.3
	Social comparison	4.3
	Making up for accident to child	4.4
2.2 Perception that accident and related event have had a negative impact on family	Beliefs re own resources/strengths	4.2
	Being strong for child or partner	4.6
	Allocation of roles	4.6
	Support from family and friends	4.7
2.3 Others' responses perceived as a threat to well-being  Blame Evaluation Comments or reactions unhelpful	Beliefs re own resources/strengths	4.2
	Monitoring child's care/question professionals	4.2
	<i>Managing blame by :-</i>	4.4
	No one to blame/concluding event was an	
	Avoiding discussions re blame	
	Justifying others' reactions	4.5
	Support from family and friends	4.7
Staff supportive	4.7	
2.4 Professionals perceived as failing	Monitoring child's care/question professionals	4.2

**Table 5c** -Threats to parental well-being and corresponding coping strategies. Super-ordinate theme 3: Other threats to well-being

<b>3. Other threats to well-being</b>	<b>Coping with threats to well-being</b>	
3.1 Observation of child's treatment	Cutting- off from emotions/auto-pilot	4.1
	Beliefs re own resources/ strengths	4.2
	Allocation of roles	4.6
	Share care/let others parent	4.6
3.2 Parental separation from child	Parental separation from child (limited)*	
3.3 Concerns about safety	Beliefs re ensuring child's safety	4.2

\* Coping strategies that was also identified as threat



*Stability of threats and coping strategies over time*

Some threats were experienced more intensely during the injury event and subsequent hospitalisation and consequently particular coping strategies predominated at these times. Other threats and coping strategies appeared to be more common when the child returned home or at the time of interview. The extent to which perceived threats and coping strategies appeared to be stable over time or vary in their intensity is summarised in Tables 6a and 6b. For each threat or coping strategy, a tick is placed under the appropriate column heading to indicate at which time it was appraised as most intense. Therefore, those threats or coping strategies which have ticks under both columns are those which remain stable over time.

Table 6a - Stability of threats over time

Threats to parental well-being (Super-ordinate themes 1, 2 and 3)	More intense during event/hospitalisation	More intense after discharge/now
<b>Super-ordinate theme 1: Intra-personal threats to parental well-being</b>		
<b>1.1 Emotional responses</b>		
Struggling with shock/panic/upset	✓	
Distressing recollections/image		✓
<b>1.2 Self blame/guilt</b>	✓	
<b>1.3 Unable to help/doubting care skills</b>		
Helplessness/parenting skills challenged	✓	
Perceiving 'medical' knowledge to be inadequate		✓
<b>1.4 Beliefs about child's injury</b>		
Appraising child's condition as serious/injury as severe/'horrible'	✓	
Child could die	✓	
Uncertainty re course and outcome	✓	✓
Fears for future/stigma	✓	✓
<b>Super-ordinate theme 2: Inter-personal threats to parental well-being</b>		
<b>2.1 Perception that accident and related events have had a negative impact on child</b>		
Pain	✓	
Changes in behaviour/behaviour unusual	✓	✓
Comparisons between child's pre and post burn functioning		✓
<b>2.2 Perception that accident has had a negative impact on family</b>	✓	
<b>2.3 Others' responses perceived as a threat</b>		
Blame	✓	✓
Evaluation	✓	
Comments or reactions unhelpful	✓	
<b>2.4 Healthcare professionals perceived as failing</b>	✓	✓
<b>Super-ordinate theme 3: Other threats to parental well-being</b>		
<b>3.1 Observation of child's treatment</b>	✓	
<b>3.2 Parental separation from child</b>	✓	
<b>3.3 Concerns about safety</b>		✓

Table 6b - Stability of coping strategies over time

<b>Super-ordinate theme 4:Coping strategies</b>	<b>More intense during event/hospitalisation</b>	<b>More intense after discharge/now</b>
<b>4.1 Distancing self from emotions generated by accident and its consequences</b>		
Cut off from emotions/'auto -pilot'	✓	
Disbelief	✓	
Using humour/euphemisms avoiding emotive language		✓
Explaining away impact on child.	✓	✓
Normalising child's reaction	✓	✓
Avoiding accident reminders		✓
<b>4.2 Overcoming difficulties/regaining control</b>		
Using 'practical' coping	✓	✓
Belief in own resources or developing strengths	✓	✓
Monitor child's medical care/question professionals	✓	✓
Beliefs about ensuring child's safety		✓
<b>4.3 Maintenance of hope</b>		
Gaining hope from healing signs	✓	✓
Gaining hope from child's "strength"	✓	
Beliefs in recovery	✓	
Caution		✓
Social comparison	✓	✓
<b>4.4 Managing blame/guilt</b>		
Attributing the accident to a unique set of circumstances		✓
No one to blame/concluding the event was an accident		✓
Avoiding blame discussions		✓
Making up for the accident to child	✓	✓
<b>4.5 Making sense of and justifying own reactions</b>		
Normalising the event		✓
Justifying		✓
Normalising their own reactions		✓
<b>4.6 Systemic management strategies</b>		
Allocation of roles	✓	✓
Being strong for their child or partner	✓	
Polarised views		✓

**Table 6b** (continued) - Stability of coping strategies over time

<b>Super-ordinate theme 4:Coping strategies</b>	<b>More intense during event/hospitalisation</b>	<b>More intense after discharge/now</b>
<b>4.7 Help and support from others</b>		
Share the care or let others parent	✓	
Support of family and friends	✓	✓
Support from health care professionals	✓	
Staff give information	✓	

## Discussion

Influences on parental well-being connected with paediatric health crises/chronic illnesses have been variably identified as cognitive appraisals of stress, particular psychosocial and illness related stressors, particular coping strategies, social support and appraisals of the health crisis and consequent events such as hospital treatment. The detailed analysis of the interview transcripts suggests that some of these influences on parental well-being were also found in this research project.

The current study explored parental appraisals of the experience of having a child who has been accidentally burned. It attempted to uncover the meaning parents attach to their experience of the event and consequences for themselves and their families. Particular attention was paid to parents' perceptions of their child's medical treatment and of their child's well-being both whilst in hospital and up until the time of the interview. The threats that parents perceived to their own well-being and the coping strategies they used in attempting to manage these threats, emerged as themes from the interview transcripts. These themes will be reviewed and compared with those suggested by the existing conceptual models and psychosocial theory. Whilst the findings from the current study cannot be directly mapped onto particular theoretical models, they indicate that the key conceptual models from the literature may inform future research into parental well-being.

For some parents, their response to the injury event and subsequent treatment would appear to share characteristics with PTSD type reactions to those threats posed to the integrity of a loved one. The intensity of these reactions varied, as did the extent to which they persisted over time. Shock, panic, anxiety and helplessness characterised parents' early responses to witnessing the injury event or discovering that it had occurred. Recollections of the event and treatment appeared to be vivid for most parents and for some these were unpredictable or associated with particular reminders which they attempted to avoid. Several parents also developed generalised fears for their child's safety.

Descriptions of distress of a more general nature, were also offered by parents. Some threats or sources of distress were common to those previously identified in empirical stress-resiliency studies of parents of children with chronic illnesses and burns. For example, some parents' descriptions of distress were linked to concerns regarding their child's behaviour. Other threats, such as perceiving one's child to be traumatised by the injury or its treatment as evidenced in

their behaviour or mood, were similar to the stressors proposed by the clinical observations of researchers such as Figley (1998). He proposes that the secondary trauma in parents is related to perceptions of their child's reaction to the traumatic event.

Overall, the most frequently identified sources of threats were related to behavioural or emotional changes that parents perceived in their children or perceptions that their child's injury was serious. Whilst these threats appeared to be most intense during their child's time in hospital, some parents continued to perceive their child as having been affected by the injury. Key strategies for coping with threats were those associated with parents being able to distance themselves from the emotions generated by the accident or its consequences and those that allowed them to remain hopeful about their child's recovery, such as comparing their situation with those in a worse position.

Mapping effective threat management onto particular coping strategies or sets of strategies was not possible due to the variation in parental stories. However, a number of threat and coping themes were found to be central to most parents' experiences. These themes and their relationship to existing conceptual models are discussed in the next two sections.

### **Threats to parental well-being**

Sources of distress for parents were associated with their beliefs about their own reaction to and role in the burn injury event and about other peoples' reactions. They were also related to beliefs about their child's well-being and perceptions of threats to this. In addition, parents described being present during their child's treatment as distressing. These threats are discussed in turn below.

Parents commonly described themselves as feeling helpless for a period of time following the event. Despite these feelings, most parents responded appropriately to their child's injury in practical terms. The extent to which parents believed they could help their child seemed to change over the time their child was in hospital, with parents developing new skills in relation to their child's medical treatment and in their emotional support for their child. The importance of beliefs about self-efficacy in relation to maintaining their child's emotional well-being has been identified in relation to parental adjustment to children with cystic fibrosis (Thomson et al., 1992, 1994). This appears to be supported by the reports of parents in this study, in that periods during

which parents perceived themselves as unable to help their child were construed by them as particularly distressing.

A consequence of being exposed to an unpredictable and uncontrollable event is to attempt to understand why the event occurred in order to re-establish notions of the world as predictable and controllable (Janoff-Bulman, 1985, 1992). Causal attributions following a threatening event have been shown to be related to emotional states (Joseph, 1999). Most parents described feelings of guilt and blamed themselves in some way for the event. The extent to which these ideas persisted over time and the distress associated with them varied. The role of self-blame has not generally been evaluated in relation to the well-being or emotional states of parents of chronically ill children and is not considered as a risk or resistance factor in stress-resiliency models most commonly associated with this literature. A small number of studies has considered the relationship between self-blame and adjustment in mothers of acutely ill newborns and children with diabetes (Affleck, Allen, Tennen, McGrade, & Ratzan, 1985; Affleck, McGrade Allen & McQueeney, 1985). These studies reached conflicting conclusions, with the former finding “behavioural self-blame” to be predictive of better adjustment and the latter finding no relationship between this type of self-blame and adjustment. Janoff-Bulman (1979) proposed that blaming one’s behaviour for the occurrence of an event is likely to be associated with better psychological outcome than blaming one’s character. Whilst the parents in the current study did not distinguish between these two types of self-blame, it could be argued that the parents who continued to perceive themselves as having failed as parents in some way were blaming their character as opposed to their behaviour. These parents appeared to have adjustment difficulties.

A number of parents described their perceptions that they were being blamed or evaluated by their family or by healthcare professionals. This also appeared to be reflected in some parents’ perceptions of the researcher. The current research indicates that perceived blame and evaluation are considered a threat to parental well-being. The relationship between perceiving that others are blaming or evaluating one’s behaviour and blaming one-self could not be delineated in this study and has not been explored empirically.

Perceptions of threats to their child was the most frequently identified theme by parents discussing affects on their own well-being. In particular, perceptions of the seriousness or severity of their child’s condition, the possibility that their child could die, and indicators that the

injury had had a negative effect on their child's well-being such as behavioural changes, were all important.

Studies of influences on parental adjustment to paediatric chronic illness and burns have reached conflicting conclusions regarding the importance of medically measured disease severity parameters for parental well-being. However, overall they suggest these factors are not relevant for well-being (Tarnowski & Rasnake, 1994; Wallander & Varni, 1998). Similarly, the results of the current research project suggest that the actual medical severity of their child's condition in terms of TBSA burned or skin graft requirements, did not influence whether parents perceived their child's injury as serious or severe at some point in time. In fact, most parents did perceive their child's injury to be severe and interestingly, at the time of interview, several parents believed the percentage of TBSA burned to be greater than medical records indicated. Believing your child's injury to be serious or severe was clearly a threat to parental well-being for parents in this study. The exact relationship between degree of perceived severity and parental well-being cannot be defined explicitly from the current research. However, other quantitative studies of parents of children with chronic illnesses have indicated that perceived severity and parental well-being may be negatively correlated (Thompson et al., 1992; Walker, Ford and Donald, 1987). Thus the more severe you perceive your child's condition to be, the worse for your well-being.

Believing that their child could die was also an important threat for parents in this study. This threat appeared to be experienced most intensely when their child was first admitted to hospital and for some parents was associated with information provided by medical staff about possible life threats. Perceived life threat was found to contribute to PTSD symptoms in parents of childhood cancer victims (Kazak et al., 1998). Although most parents continued to believe that their child had suffered a serious or severe injury, the extent to which beliefs about fatality persisted over time or impacted upon parental well-being was unclear. Qualitative research by Mason and Hillier (1993) indicated that parents who thought their child might die were less likely to have come to terms with their child's thermal injury six months after the accident. Interestingly, three parents, all of whom had recalled fears that their child might die, reported generalised fears for their child's safety at the time of the interview, suggesting that their beliefs about the accident may continue to present a threat to parental well-being. As an individual's memory of perceived threats may change over time as new information is incorporated, the extent to which such threats present a challenge to well-being, may change (Schwarz, Kowalski and McNally, 1993). Differentiating between current beliefs about life threat and recollections of this



perception closer to the event may be useful when investigating potential risk factors for parental well-being.

Changes in their child's behaviour which parents connected with the burn injury, were associated with distress in parents. The extent to which believing an injury or illness has had a negative affect on your child has not been directly addressed in studies of parental adjustment to their child's chronic illness. However, measures of perceived concerns regarding specific disability-related problems were found to be correlated with maternal adjustment (Noojin and Wallander, 1996). In this current research, those parents who indicated that their child had or was still displaying behaviour problems at home, varied as to whether they cited it as their main source of stress above other concerns. Similarly, most parents questioned in a study by Meyer et al. (1994), whose burned children scored above the mean on a standardised behaviour problem checklist, attributed their own distress to their child's behaviour but, unlike the current research, they attributed their concerns to other sources as well.

During hospitalisation, believing their child to be in pain, particularly during medical treatment such as debridement, was a source of considerable distress to parents. The memory of this remained particularly distressing for two parents in the long-term and both became distressed at this recollection during the interview. One described still having recurring nightmares about their child's distress during treatment ten months after the event. The other reported anxiety and depression (for which she was receiving medication) and recurrent dreams of being unable to protect her children. However, other parents felt differently, with some feeling they had gained strength from being there during treatment and others acknowledging that they found it too distressing to be with their children at these times. These results differ from those in a study by Doctor (1992), who suggested that most parents enjoy an increased sense of competence as a result of participation in treatment for their child's burn injury.

### **Coping strategies**

Attempts to manage particular threats to well-being often appeared to be associated with a number of coping strategies. Some of these strategies appeared to be more useful for parents when the injury first occurred, with others playing a part later on.

The coping strategies used by those parents originally identified by the burns unit staff as “coping” did not appear to differ from those identified as “not coping”. Of those parents who appeared to be most distressed at the time of the interview, two of the families had previously been identified as coping by staff and one as not coping well.

Coping strategies clustered around several sub-ordinate themes. These themes related to: strategies which enabled parents to distance themselves from the emotional consequences of the injury; those which helped parents overcome difficulties and regain control; those which helped them maintain hope and manage blame; those relating to the support they received and those which related to the parents attempts to cope as a family.

In general, parents attempted to distance themselves from the emotions generated by the burn injury event and its consequences for themselves and their child. Initially, disbelief at the seriousness of their child’s injury and feeling numb to emotions, appeared to allow parents to cope with practical aspects of responding to the accident and adopt coping strategies that were largely problem focused. Lubinsky (1994) suggests that similar responses are presumed by others to be features of denial but are in fact the results of dissonance between what is perceived and information that is given. Whilst this is sometimes not viewed as ‘adaptive’ it appeared to be so (at least initially) for parents in the current study. Davis (1993) offers a similar explanation for parents’ difficulties in coming to terms with illness diagnosis or accident. He suggests that as parents’ initial responses may be based on the pre-existing constructs of trivial childhood illnesses, it may take time to develop new constructs about their child’s health and thus interpret information that is incongruous.

Attempts by parents to distance themselves from the emotions as a coping strategy is also indicated by two of the studies found in the quantitative burns literature. Blakeney et al. (1993) found that parents PSI depression scores were highest two years post-burn but then from year three onwards scores decreased, such that by years four to five, they were lower than that of the reference population. These authors site this as evidence of a defensive coping strategy. Le Doux et al. (1998) also reached similar conclusions. They found that family cohesion was reported at levels of above that of the reference population post-burn for parents whose children had adjusted well, but was not related to any measures of parental well-being. This was suggested as indicative of parents denying their emotional problems but pulling together as result of the burn. In the current study, the parents used a number of strategies that may have served to

help them manage distress and disturbing recollections of the event that could also be considered as “defensive”. These included avoiding reminders, attempts to find evidence that their child had not been affected by the injury and using humour and euphemisms when discussing painful memories. In this way, the threat associated with parents’ initial appraisals of the event appeared to be reduced.

Believing that they had developed resources or strengths to help their child as a result of the burn injury experience, appeared to represent an important coping strategy for some parents in this study. This was also a factor proposed as aiding recovery from secondary traumatic stress by other researcher-clinicians (Figley, 1998). Unlike Barnes’ (1998) study, this study suggests that parents may not initially have concerns about handing over care to professionals, but may subsequently make attempts to regain control through questioning staff or actively monitoring the care provided. Although regaining control appeared to be important, most parents felt that staff support, in terms of listening to parental concerns and offering reassurance, was required to maintain the control.

Overall, continuing to believe that their child was suffering negative effects from their injury at the time of the interview appeared to be associated with current distress. Evidence cited included a child’s behaviour problems, perceived trauma reactions such as nightmares and unusual behaviour that could not be normalised or explained. It is possible that this evidence interfered with parents’ attempts to distance themselves from events or their ability to develop a sense of self-efficacy in relation to being able to maintain their child’s well-being. Alternatively, it may challenge beliefs that parents have developed strengths or skills with which they can help their child.

Although ‘practical’ coping and other attempts to overcome difficulties or regain control through the adoption of problem solving strategies (such as attempts to ensure the accident would not recur) were used at various points in time, they were not necessarily predictive of future approaches. This highlights the need for longitudinal studies to identify the usefulness of adopting different strategies at different times. However, in the short term these responses appeared to be perceived as temporarily effective in alleviating distress. This supports Wallander and Varni (1998) and Thompson et al.’s (1994) contentions that they represent a strategy for maintaining parental mental health.

Strategies aimed at maintaining hope were used by parents from the time of their child's hospitalisation until the interview. Many of these strategies appeared to have their basis in social comparison with parents whose children were less fortunate or those whose children were equally badly burned but coping well. Researchers such as Taylor and Lobel (1989) have identified similar strategies for women with breast cancer. Taylor (1983) suggests that good copers may act as role models and that comparison with those worse off aided positive self-evaluation and may therefore be ego enhancing at a time of threat.

To tackle the uncertainty regarding the course and outcome of their child's condition and worries for their child in the future, parents employed a number of coping strategies. Some expressed belief in their child's recovery or highlighted the continuing signs of healing that they observed from changes in the appearance of their child's scar. Others attempted to explain away any impact the event may have had on their child through normalising their child's reactions. Taylor and Brown (1988) suggested that similar approaches, whilst seemingly unrealistic at times, may be characteristic of most peoples' thoughts. They argue that these strategies may be especially useful when threatened as they may serve to filter more negative information. For some parents, ongoing uncertainty itself also represented a source of hope for the future.

Parents interviewed in this study clearly indicated the impact of the burn injury on the roles adopted by each parent in relation to the event and their child's treatment. It has been suggested that pre-existing family stories regarding health and response crises may prescribe the way families interact and respond to health crises (Shaw and Halliday, 1992). In the current research, the allocation of these roles seemed to be based on pre-accident family beliefs about individuals' coping styles and the need to be strong for others. Other attempts to manage threats as a family were reflected in the polarised positions couples were observed to take in some situations. Adoption of polarised stances has similarly been observed in narrative family therapy case studies of parents facing the loss of a child (Byng-Hall, 1997). This author suggests that it may represent a couple's way of handling painful material, which would also seem to be the case in this research.

Perceptions of blame, evaluation by others and self-blame, were all indicated as being potentially threatening to parental well-being. Being able to normalise the event through contact with other parents and the wider community was an important strategy for managing these perceptions although parents also placed significance on comments made by staff. It could be hypothesised

therefore, that parents who are isolated, lone parents, or those who have few opportunities to discuss their perceptions with others, may be at greater risk from self-blame and being blamed by others once they leave hospital. This certainly appeared to be the case for one parent (Sarah's mother), in the current research.

Support offered by family was invaluable for most parents especially when their child was still in hospital. Support from staff in the form of both information and protection from threats to well-being (for example, being assured that the accident was not your fault), was also valued.

### **Reflections on the research and interview process**

In order to check the impact of the interview on the interviewees and the validity of interpretations, the parents were asked to reflect on the process and subsequently on the researcher's analysis of the interview.

An important tenet of the research paradigm chosen for this study was a commitment to researcher reflexivity and critical self-scrutiny. Therefore, the researcher kept a diary of her reflections on each interview and her reactions to the analysis process and discussed these reflections with a supervisor. These reflections are viewed as part of the data and are also an important part of addressing the issue of transparency in the research process (Mason 1996).

#### *Parents' reflections on the interview process*

Despite their observable distress during the interviews, all parents stated that they were pleased they had taken part. Some parents also stated that it had prompted them to reflect on issues they had not considered prior to the interview or that it was the first time they had discussed the events in depth. Most described their motivation for taking part as helping other parents through similar experiences. All stated that their experiences had been stressful and described recalling a number of distressing recollections of the event and its consequences during the interview itself. When re-contacted by telephone as part of the procedure for verifying the researcher's interpretations, five parents reflected that they had experienced the interview as helpful with James' mother stating that it had "taken some of the weight off her mind".

On the whole, parents appeared to be coping well at the time of the interview (see appendix 7b for Researcher's reflections on interviews with parents). However, all but one parent felt that

being interviewed earlier would have been too distressing and that talking to someone at the time of hospitalisation would have been difficult. Regardless of time that had elapsed since the injury, most parents felt that the time at which they were interviewed was appropriate. These reflections were at odds with the distress most parents showed at the interviews. This suggests that distress regarding the accident was not simply ameliorated by time but was affected by different coping strategies that may or may not be effective when parents discussed their experiences with researcher. Parents' expressed interest in helping other parents and the indications that they had benefited from the interview experience were perhaps representative of efforts to re-story the accident as a stressful event from which they had been able to recover. The apparently contradictory positions adopted by parents at different times were exemplified by Harriet's mother. Although she had sounded anxious during the pre-interview telephone call, she did not become observably distressed during the interview and suggested that she was no longer affected by the experience of her child being burned. However, she then expressed her relief that the interview had not been "as bad" as she had anticipated.

Several parents reported that they had noticed subtle changes in their perceptions of threats when they were contacted for a second time, on the whole suggesting that some threats were now less dominant than previously. However for two parents this contrasted with some of the comments they had made at the initial interview. This suggests that adjustment to their child's accident was an ongoing process. This is supportive of another qualitative study by Mason (1993) who suggests that mothers' responses to their child's injury are dynamic, with different events causing parents to travel back and forth between phases of a response continuum.

For a more detailed account of these reflections see Appendix 7a.

#### *Researcher's reflections on the interview process*

Although parental responses to the researcher varied, most talked about the various aspects of their experiences with little prompting from the interviewer. This was especially noticeable in their descriptions of the lead up to the accident, the event itself, and their practical responses to the accident. Whilst these descriptions may have been well rehearsed and required by other professionals, their nature appeared to reflect a desire to ensure that the researcher did not attribute blame to any of their actions. It seems likely that despite confidentiality being assured and the fact that the researcher's position had been made clear, parents viewed her as part of the hospital and therefore potentially in a position to evaluate them. This made the researcher aware

of the power differential between parents and healthcare professionals and the vulnerability of parents who may find themselves in a position where they may perceive that their beliefs about their care skills are at risk of being challenged.

Interviewing parents who became distressed made the researcher question her ability to separate herself from her clinical role. In practice it was necessary to stop audio-taping and offer these parents the opportunity to stop the interview altogether, to have the interviewer listen and support them. In line with feminist researchers, the interviewer did not view this approach as problematic. Renzetti and Lee (1993) suggest that it is important that participants are viewed as having real emotions and that whilst attempting to remain objective the interviewer needs to adopt the role of an empathic listener. Interestingly, having interviewed several participants who had become distressed, the researcher found herself questioning whether those who were less emotive were either less concerned or attempting to control their emotions. It is possible that the researcher's dilemma may mirror the responses of other professionals and hinder them in providing appropriate support or exploration of concerns.

Interviewing couples, whilst challenging for the researcher, gave her the opportunity to observe interactions and systemic strategies for coping. A common problem cited by researchers interested in family influences on parents and children with paediatric health problems is a reliance on paper and pencil methods to describe family functioning (Wallander and Varni, 1998). The methodological approach taken by the current research is supportive of suggestions for more observational studies of family interactions.

During the analysis process, the researcher found it difficult not to interpret or attach significance to every statement offered by parents. Validity checks through feedback to parents and a supervisor reading transcripts and highlighting significant statements, were useful in counteracting this tendency. In addition, the researcher was aware that her knowledge of related research areas and experiences of interviewing parents of children with disabilities were potential sources of bias during the analysis process. Efforts were made to counterbalance these biases by listing them prior to the analysis (see Appendix 7b) and discussing potential interpretations with other researchers and supervisors.

For a diary of the researchers reflections on the research process, impressions following each interview and interpretations of parents' reflections on the researcher's summaries when they were contacted by telephone, see Appendix 7b.

### **Clinical Implications**

A number of potential clinical implications can be drawn from the comments parents made in this research. Some of the implications are relevant to traditional therapeutic interventions while others are more relevant to specific interactions with healthcare professionals which may have ramifications for staff training. The threats described by parents sometimes reflected those suggested as risk factors for parental mental health by the stress-resiliency models, whereas other threats could be categorised as those of a post traumatic stress reaction to an event. The possibilities for intervention are discussed below.

Acknowledging the adaptive denial that parents demonstrate initially is important for therapists and staff members providing information for parents. As a result of this, providing information at regular intervals and repeating it, may ensure that parents understand more about their child's injury. However, given the threat of helplessness and perceptions that existing care skills are being challenged, parents may consider information alone unhelpful in the absence of strategies for aiding the child's care. Therefore, it seems important for staff to ensure that options or advice regarding the role they can play in their child's care are presented to parents as well.

Involving parents in their child's treatment has been recommended by previous research. Although the option to become involved in treatment was clearly important for some parents, it was traumatic for others. Debriefing following treatment may be an option but has not received much empirical support for reduction in trauma symptoms on standardised assessment measures (Canterbury & Yule, 1999). However, a number of studies reviewed by the same authors suggest that trauma victims found this helpful. Alternative therapeutic strategies such as cognitive therapy or exposure treatment for PTSD, could be used if it was determined that parents met criteria for this disorder or were experiencing relevant symptomatology.

Support for parents from healthcare professionals was particularly valued when their children were first admitted to hospital. Parental beliefs regarding their ability to provide appropriate care for their child both in and out of hospital appeared to be vital for regaining control and adopting



more problem focused strategies for coping. However, regaining control in a situation where options for control are limited, such as in a hospital, may increase perceived stress levels (Evans, Shapiro, and Lewis, 1993). Thus, maintaining initial support levels from staff through reassurance and information provision (as recommended by parents in this study) seems to be important even when parents appear to be coping well.

As monitoring their child's care and asking questions about it seemed important for a number of parents' self efficacy, the impact this may have on hospital staff needs to be considered. Reframing this behaviour as an indicator of parental attempts to cope may aid staff understanding rather than staff becoming frustrated by seemingly repetitive or pedantic questioning.

Whilst uncertainty regarding the eventual outcome of their child's injury, both in terms of their physical appearance and their emotional well-being as they grew up, remained a source of distress for parents, they either distanced themselves from these consequences or were cautious. Several parents expressed their suspicions that their child's scar might not improve further but still discussed the possibility that they may be wrong. For many parents these strategies allowed them to remain hopeful but realistic. Offering training to staff that may help them mirror this position by providing information about potential outcome while also offering more positive examples of recovery, may therefore be useful.

Perceiving others to be blaming or evaluating and self-blame, were all threatening to parents and affected well-being. Burns to under fives most commonly occur at home with parents in close proximity (Wilkinson, 1998), so the possibilities for attributing the child's burns to other people or the child, are therefore limited. As staff necessarily have to be vigilant for non-accidental burn injuries and need to establish the exact burn circumstances at a time when parents feel vulnerable, the scope for parents to feel blamed is significant. Societal influences such as believing that burn injuries are often associated with neglect, may also provide the backdrop for some of the ways in which parents and professionals "story" the causes of burns. Whilst addressing blame issues appears to be important for some parents' coping, it seems necessary for investigations to be normalised both during and after they occur and options for parents to discuss these feelings to be provided. Narrative therapists' ideas regarding exploration of alternative stories of the event and the influence of the currently held story on parents' actions, may also be usefully trialed (e.g. White & Epston, 1990).

Family interventions have been suggested as important by both proponents of PTSD models of parental adjustment and the stress-resiliency models. Interventions aimed at facilitating coping skills have been trialed for parents of children with leukemia and although helpful at the time of diagnosis, were not related to subsequent parental adjustment (Kupst and Schulman, 1988). In line with Le Doux et al. (1998), the current study suggests that more systemically oriented family therapy interventions may be more appropriate. Coping strategies described by parents that involved or affected other family members included being allocated a role, not discussing the event, being strong on someone else's behalf and adopting polarised views regarding key issues. Whilst it is not suggested that these are generally pathological, for some parents the use of these strategies was detrimental to their well-being. The issues identified therefore do not appear to be around coping skills per se but are associated with open communication and the development of a mutually satisfactory response to the event. Therefore, proposals by Figley (1989) for systemic working with traumatised families may be useful to consider. These include: allowing each family member to tell their story of the event and encouraging others to hear them; reframing ideas about the event or problem such as blame; developing a family consensus about the event; shifting attention from the identified patient to consider "individual's healing theories" and identifying alternative family and individual coping strategies if necessary.

Finally, the commonly adopted strategy of parents distancing themselves from the emotions generated by the accident and its consequences, may affect both the depth and pace of therapeutic interventions offered. In addition, the importance of strategies that allowed parents to remain helpful, may interfere with therapists who wish to help parents 'accept' the potential injury consequences. Other authors have suggested cognitive restructuring so that parents gain more realistic expectations about their child's recovery (e.g. Holaday & McPhearson, 1997), but the current study implies that these interventions should be approached with caution. When parents reflected on the interview process, they acknowledged that even if they had wanted to have such a conversation when their child was in hospital, it would have been difficult to do so practically. In addition, they suggested that intervention from a mental health professional might be viewed as suggesting that they were not coping and prevent them from accessing such a service. Low key interventions from known medical staff or facilitated groups, aimed perhaps at normalising some of the parents' reactions, may prove at least initially, to be more appropriate.

## **Methodological issues**

Some methodological issues were clear from the outset of this research - the limitations on generalising the findings beyond the sample interviewed and establishing reliability such that exact replication of the research could be undertaken. In addition, following the recommendations of other qualitative researchers, the need to consider verification methods for establishing validity in the research were incorporated into the analysis and presentation of findings (Mason, 1996; Smith 1996; Turpin, Barley, Beail, Scaife, Slade, Smith & Walsh, 1997). Other issues, such as the limits of the sampling strategy adopted and the considerations for the depth of interpretative phenomenological analysis, emerged during the research process.

### *Generalisability and the sample obtained for this study*

Most qualitative researchers acknowledge that generalising findings from their study to a wider population on the basis of their findings being statistically representative is usually not possible due to sample size and considerations regarding access to participants (Mason 1996). In the case of the current research, it could be argued that through the use of maximum variation and quota sampling techniques, steps were taken to ensure that the sample represented a wide range of experiences and that therefore there are no reasons to conclude that the sample was particularly atypical. Further support for this argument can be drawn from the findings that parents who were considered to be coping well and whose children were not severely burned, identified similar constructs of threats to themselves and their child as those who had children who were severely burned and required intensive care or skin grafts.

It is hoped that the presentation of sufficient data to demonstrate the variability within sub-themes will allow reflections to be made about possible predictions for other parents and their applicability to be duly assessed. The presentation of differences between those parents who currently report or demonstrated most distress and those who did not, alongside researcher reflections for these parents, are also used to aid the reader in evaluating the validity of the research.

The limitations to the sampling approach include the time it required of extremely busy medical staff and difficulties in accessing those parents who staff assessed as not coping well. The possibility remains that those parents who did not volunteer to be interviewed may have been those whose current coping strategies consisted of avoidance of reminders of their experiences.

### *Reliability and Validity*

The reliability of qualitative research cannot be assessed in terms of the consistency of the research method or tool for producing the same measurements or results, as many qualitative research methods are non-standardized by their very nature. As the philosophical stance of most qualitative researchers is to uncover how the social world is experienced or understood, it attempts to produce data using flexible methods that allow researchers to get closer to the 'real life' contexts of the participants and prioritise their understandings (Mason, 1996). Mason (1996) suggests that an overemphasis on measuring reliability or accuracy may preclude the researcher from considering what is being measured.

The challenge of an interpretative analysis (especially IPA, with its commitment to understanding the thoughts and beliefs of participants that may not be immediately obvious), is in demonstrating the validity of the researcher's analysis. The depth of engagement with the data may lead to the presumption that the researcher's biases are guiding the analysis as it may not be clear to the reader how conclusions regarding meaning were reached. Judging the depth of interpretation was at times difficult and therefore required that the researcher use a number of external validity checks as well as ensuring that the coherence of the arguments presented were continually checked for representation in the text.

Several approaches were taken towards ensuring the validity of the analysis in this research. Firstly, as advocated by other researchers using the same method (IPA), the researcher as far as possible attempted to "bracket" her own preconceptions and knowledge of the area to be researched (Smith, 1996). In order to do this it was important to reflect on interviews and interpretations through keeping a diary and discussion with supervisors. Secondly, attempts were made to show a chain of evidence from themes and reflections back to the interview transcripts and diaries such that an independent auditor could follow the process and consider alternative interpretations of the data (Turpin et al., 1997). Thirdly, other researchers were asked to match data units to themes that were then compared with existing interpretations and, finally, data interpretations were checked with participants.

### **Future research**

Some suggestions for future research have already been made in the course of this discussion. Further ideas for future research include the following. Firstly, multi-variate quantitative research incorporating the relevant mediators of well-being identified by the current research could be carried out. Measures that examine parents' beliefs about changes in their child's behaviour since the burn injury and not just behaviour problems, may be usefully incorporated into these studies. Perceived burn severity instead of objectively measured burn severity and the relationship to parental adjustment could also be included. Secondly, further consideration of the applicability of trauma models for understanding parental responses to their child's burn injury, especially its treatment, are warranted. This perhaps should be considered early in the process of adjustment as it is possible that experiencing PTSD symptoms in relation to accident reminders may prevent parents from engaging sufficiently with services in the future. Finally, further investigations into the whole family system's response to a paediatric burn injury could be considered.

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**Appendix 1 – Ethics Committee correspondence**

Our ref: **R/E/16/99**

July 1999

Dear

**RE: APPLICATION R/E/16/99: THE IMPACT ON PARENTAL WELL BEING OF CARING FOR A PRE-SCHOOL CHILD WHO HAS BEEN ACCIDENTALLY BURNED: A PHENOMENOLOGICAL INVESTIGATION OF PARENTS' EXPERIENCES OF THE HOSPITALISATION AND AFTER CARE OF A CHILD WHO HAS BEEN BURNED**

Thank you for submitting the above protocol which will be considered at the next meeting of the Paediatric Research Ethics Committee on Thursday 15th July 1999 at 4.40 pm in the **Boardroom**, NHS Trust:

You are invited to attend to answer any specific questions raised.

Please contact the above extension to confirm your attendance.

Thank you.

Yours sincerely

**Chairman  
Paediatric Research Ethics Committee**



Our ref 1r/e/16/99

16 July 1999

Dear

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RE APPLICATION R/E/16/99 THE IMPACT ON PARENTAL WELL BEING OF CARING FOR A PRE-SCHOOL CHILD WHO HAS BEEN ACCIDENTALLY BURNED A PHENOMENOLOGICAL INVESTIGATION OF PARENTS, EXPERIENCES OF THE HOSPITALISATION AND AFTER CARE OF A CHILD WHO HAS BEEN BURNED

Thank you for attending the 15th July meeting of the Paediatric Research Ethics Committee

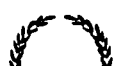
As you are aware the Committee requested a minor amendment to the consent form and copies of the letters of support from  
Consultant Clinical Psychologist and  
, Consultant Burns & Plastic Surgeon

The Committee are happy to approval this study and look forward to receiving the revised consent form and letters of support.

We wish you well with this study

Yours sincerely

Chairman  
Paediatric Research Ethics Committee



Our ref: 2R/E/16/99

23 July 1999

Dear

RE: APPLICATION R/E/16/99: THE IMPACT ON PARENTAL WELL BEING OF CARING FOR A PRE-SCHOOL CHILD WHO HAS BEEN ACCIDENTALLY BURNED: A PHENOMENOLOGICAL INVESTIGATION OF PARENTS' EXPERIENCES OF THE HOSPITALISATION AND AFTER CARE OF A CHILD WHO HAS BEEN BURNED

Thank you for your prompt reply to my letter dated 5th July 1999, in which you satisfactorily addressed the points raised by the Research Review Committee. Therefore, I am happy to give approval for this study through 'Chairman's Action'.

With best wishes.

Yours sincerely

Chairman, Research Review Committee

cc



**Appendix 2 -Recruitment criteria for Burns Unit staff**



**Re: Doctoral Research for Clinical Psychology Trainee - \*\*\*\*\* (supervised by \*\*\*\*\*)**

**Project's working title:**

The impact on parents well being of caring for a pre-school child who has been accidentally burned: a phenomenological investigation of parents' experiences of the hospitalisation and after care of child who has been burned

**Project aim:** To describe from the parents' perspective the experience of parenting a child who has been burned through exploring what impact burn injury event and its after care has on parental well being and how this event(s) is appraised by parents.

This above is just a short summary of my research . Over the next 6 months I hope to interview at least 12 parents about their experiences. I hope to approach parents via a letter either sent through yourselves at the scar management clinic or from Mr \*\*\*\*\* . But before I do this I need to identify a pool of parents to approach initially . This is where I would be most grateful for your help.

**The criteria for the research are :**

4 children who have less than 10%TBSA burns and who you feel overall have coped well  
 4 children who have less than 10%TBSA burns and who you feel overall have not coped well  
 4 children who have more than 10%TBSA burns and who you feel overall have coped well  
 4 children who have more than 10%TBSA burns and who you feel overall have not coped well  
 For at least two of the above to have had skin grafts

**The parents must be :**

- parents of children who were under 5 at the time of the injury .
- parents of children who were admitted to hospital for more than one night with a primary diagnosis of burn injury.
- parents whose children were burned with in the last 6 months (although we may need to extend this period to 18 months if not enough people reply)
- parents of children who have been discharged from the hospital ward for at least 1month

**The parents must not be:**

- Parents whose child's injury may have been inflicted non-accidentally
- Parents whose child has another chronic illness as well

Many thanks in anticipation of your help ,  
 \*\*\*\*\* ( Clinical Psychology Trainee)

**Appendix 3 Information for parents**

- **Covering letter from consultant**
- **Letter from researcher to potential participants**
- **Information sheet for parents**
- **Consent form**

**DEPARTMENT OF PLASTIC SURGERY**

**Dear**

**I enclose a letter from a researcher who is interested in finding out more about your experiences of caring for a young child who has had a burn injury. I have not passed on your details to her, if you reply with your telephone number or address she will then contact you. Please leave a message or send back the reply slip if you feel you can help with this research.**

**Helping in this research will increase our knowledge about how to help parents in the future.**

**Yours faithfully**

**Consultant Plastic Surgeon**

Dear Parent(s),

I have asked Mr \*\*\*\*\* (the Consultant Burns and Plastic Surgeon in charge of your child's care when he/she was admitted to the Burns Unit at \*\*\*\*\*) to send this letter on to you to see if you could help with some research.

The research is to look at what effect you think looking after a child who has been accidentally burned has had on you and your family both when it first happened and during the last few months. The idea is to find out more about what parents felt. This is so that we can come up with ways of helping parents and healthcare professionals when a child is first injured and when they are looking after a child afterwards.

To find out what your views I would like to talk to you. I am an experienced interviewer and Clinical Psychologist in the final stages of training. This research forms part of my course but will be supervised by \*\*\*\*\* the Clinical Psychologist who works on the burns unit at \*\*\*\*\*. The discussion will take approximately an hour depending on how much you want to say. It will take place in your own home (or where ever is most convenient for you). You can stop the discussion at any time.

**We do not know your name(s) or details. We only know that your child has been admitted to the Burns Unit due to an accidental burn injury that has occurred over the last 18 months.**

You have had an experience unique to each parent and whilst it is hoped you will share your experiences you can say as little or as much as you want. With the help and ideas of parents like yourself the research can go forwards. All your details will remain private at all times. At no time will the details of your discussion be communicated to your doctors, nurses or any other services' staff.

**If you feel you can help with the research please fill in the reply slip below and post it back to us in the pre-paid envelope as soon as you can . I will then contact you by letter or phone to arrange a convenient time to meet.**

For more details about the research an information sheet is enclosed . However if you feel you have any questions or need to know more you can contact me. Leave a message that you wish to be phoned on \*\*\*\*\* with a contact number.

Yours sincerely

\*\*\*\*\*

Clinical Psychologist in Training

☺: \_\_\_\_\_  
**REPLY SLIP**

I / We(full names).....would like to volunteer to discuss my/our experiences of caring for a child who has been burned.

**Please give details of how I can contact you below**

(either Home and/or Work telephone number or an address for correspondence)

.....

Name of child.....

Child's date of birth .....

Date when the burn injury happened.....

## Parent Information Sheet

### The impact of having a child who has been accidentally burned - parents' experiences

A study is being undertaken by: \*\*\*\*\* (Clinical Psychologist in training)  
 With the collaboration of : \*\*\*\*\* (Consultant Burns and Plastic surgeon)  
 \*\*\*\*\* (Consultant Burns and Plastic surgeon)  
 \*\*\*\*\* (Consultant Clinical Psychologist)

#### Purpose of the study

The research is to look at what effect you think looking after a child who has been accidentally burned has had on you and your family both when it first happened and during the last few months. The idea is to find out more about what parents felt. This is so that we can come up with ways of helping parents and healthcare professionals when a child is first injured and when they are looking after their child afterwards.

This study is supported by the \*\*\*\*\* Training Course. The researcher (\*\*\*\*\* ) is a Clinical Psychologist in the final year of training from the \*\*\*\*\* Clinical Psychology Training Course and the study forms part of a research for a Doctorate in Clinical Psychology.

Taking part in this study does not mean you or your child need to see a psychologist.

#### How will parents be chosen to taken part?

You will receive a letter with this information sheet from your Doctor at the hospital asking you if you would like to take part with a slip to fill in and send back. Alternatively nurses at the scar management clinic may give you a letter and information.

If you send a reply slip saying you agree to take part in the study the researcher will contact you by letter or phone as soon as possible to make arrangements.

The researcher will have no knowledge of your name, address or details until you volunteer agree to be contacted

**N.B. Not taking part in this study **will not** affect your child's care in any way**

#### What will happen if you volunteer to take part in the study?

To find out what your views are the researcher would like to talk to you about how having a child who has been burned as affected you and your family, how you felt and what has been helpful or unhelpful. The researcher is experienced in interviewing parents whose children have been in hospital.

The interview will probably take between 1 and 2 hours but may occasionally last a little longer. You can say as little or as much as you like and you do not have to answer any questions you do not want to.

With your permission the interview will be taped to help the researcher remember what you said. The tape will be listened to by the researcher and her supervisors only. You will not be named on the tape and the hospital medical staff will not listen to the tapes.

After the study all the tapes will be destroyed

**N.B. You can stop the discussion at any time and withdraw from the research at any time . This will not affect your child's care in any way**

#### Where will the interview take place?

The interview will take place in your own home (or wherever is most convenient for you). The researcher will need to talk to you twice (or write to and phone you) to check that her summary of what you said is correct. When the study is finished a short summary of what all the parents said will be sent to you if you request it.

#### Confidentiality

A written record of the discussion will be kept but it will always remain confidential and stored safely under a code number not your name. The medical staff involved will only receive a general summary of the comments made by all the parents who have volunteered to be interviewed. This will make sure that none of the comments you make are identifiable by your doctor or nurses.

#### Postage and travel costs

To send any letters or reply slips you will be provided with a pre-paid envelope or refunded the cost of postage. You will also be refunded any travel expenses if you prefer to meet at a place other than your home.

#### Questions and Queries

Please get in touch if you would like to know more. You can contact \*\*\*\*\* on \*\*\*\*\* or leave a message that you want to be called back with \*\*\*\* the secretary on the same number. You can also contact \*\*\*\*\* by phoning \*\*\*\*\*

## Consent Form

### The impact of having a child who has been accidentally burned - parents' experiences

I..... volunteer to discuss how having a child who has been burned has affected my family and me. The purpose of the study is to come up with ways of helping parents and healthcare professionals at the time when children are burned and afterwards.

The study has been explained to me by .....(my child's doctor / nurses at the clinic)

I understand that taking part in the study is voluntary and that I have the right to withdraw from this study at any time without stating any reason and without my child's treatment being effected.

I have also read the patient information sheet for parents involved in this study and I understand that I can ask for further information relating to the study from the supervising doctor/nurses or research team.

Signature of parent/guardian ..... Date .....

Name of researcher (block capitals) ..... Date .....

Signature of researcher .....

**Appendix 4 - Interview schedule**



## **Interview Schedule**

### **Introduction:**

- Introduction of interviewer to participant
- Explain aims of research and what taking part involves
- Inform participants that they will be contacted again
- Explain confidentiality and what will happen to the interview material
- Ask for permission to tape interview and explain what will happen to taped material
- Remind interviewee that they do not have to answer all the questions and that if they become distressed by the interview it can be stopped

### **Background Information:**

- Obtain participants age, marital status, occupation, members in family, ages of children, location of extended family, time spent in current living situation.
- Obtain burned child's name, age at the time of the accident and current age
- Length of hospital admission , including any admissions to the ICU and treatment for any non-burn related injuries
- Time since discharge and number of visits can recall making to consultant/registrar and scar management clinic

### **Circumstances of accident and hospitalisation:**

- How did ..... come to be burned? What happened?
- Who was present at the time? Where you or any other family members injured in any way due to the accident?
- If you were not there how did you come to find out about the accident?
- What was this experience like for you?
- What do you think the experience was like for the rest of your family
- What happened when .....was admitted to hospital?
- How did you feel when ..... was admitted to hospital? What were you most concerned about?
- How did you feel while ..... was still in hospital? What were you most concerned about?
- What was the experience like for the rest of your family?
- How were you involved in your child's treatment ? What was the experience like for you?
- Did you have to miss any work due to the accident?

### **Description of child's injury and perception of impact on child**

- How severe was your child's burn? Which parts of their body were burned
- How long do/did you think it will/would take before the injury healed?
- What does the scar look like to you ? / Do you think the scar will change? How?
- How if at all do you feel the injury has effected your child? In what ways? How has this effected you? How has this effected your family ?
- How do you think your child has coped with the burn injury /accident? Have you noticed any changes in your child since the injury? How, if at all, has this effected you or your partner ?

- How had did your child behave after the accident at home/nursery/other people's houses? What did you make this?

#### **Discharge from hospital ward and rehabilitation:**

- How did you feel when ..... was discharged from hospital ? What were you most concerned about ?
- What was the experience like for the rest of your family?
- How long do you think it will take .....to recover? What do you think will help?
- What was/is the experience of attending the clinic/ follow-up appointments like?
- What type of treatment /burn care were you involved in after your child was discharged from the ward? Was anybody else involved in this treatment ?How did this effect you and your family? How did you cope?
- How did you feel when .....went to school /nursery after the injury?

#### **Impact on parent**

- Do you feel you have changed since the injury? How?
- What affect as the burn had on you as a parent?
- What affect has the injury had on your approach to parenting....?
- How if at all has this changed since the injury

#### **Coping / Support**

- How do you feel you coped at the time of the injury /accident ? How do you feel you coped whilst ..... was in hospital / when he she came home ? How do you feel you are coping now? What did you find most difficult?
- What helps you cope? What has been most helpful? What methods do you use? Have you used these methods before? How useful have these methods been?
- Overall how has ..... being burned effected you family?
- What helps your family cope?
- What type of support (if at all) have you received? Who has supported you? What type of support have you found most helpful?
- How often has the accident/injury been talked about since it occurred? With whom do these discussions occur?

#### **Expectations for the future**

- What concerns do you have about the future?
- How do you think the burn will effect your child in the future?
- How do you think the burn injury will effect you and your family in the future?

#### **Reflections on interview**

FINALLY – How have you found doing this interview?

When would you have preferred to have this conversation?

**End interview:** Thank participant for their co-operation and remind them that will be contacted once more. Discuss contact numbers if upset or feel upset when researcher leaves.

**Appendix 5 - Example of parent summary**

## Summary of Interview with Parent(s) – John

**Effects of Burn Accident – This is a list describing what impact you felt the accident had on you and what you found distressing.**

Shock, panic and upset – losing it when realised water wasn't lukewarm, feeling hysterical but lady next door tried to help E\*\*\*\* calm down. D\*\*\*\* finding it hard to watch John when skin scrubbed and dressings changed.

Distressing memories/reminders – remembering hearing John's scream which wasn't his scream at all (E\*\*\*\*). D\*\*\*\* having nightmares about when they took him to clean his skin. Finding it hard to use the bathroom where it happened preferring to have a shower at your mums. Feeling unsettled and uncomfortable in the flat where the accident happened.

Self Blame - E\*\*\*\* feeling guilty when leaving O\*\*\*\*\* and the Russian doctor saying it was a very bad accident.

Feeling helpless/normal caring difficult – feeling both powerless to help when he was saying Dad, Dad during dressing changes (D\*\*\*\*). Not being able to lift him up and move around with him (E\*\*\*\*). Feeling like he didn't need you when he was OK when left with the nurses for a few minutes(E\*\*\*\*).

Seriousness severity of injury – skin coming off in sheets (E\*\*\*\*). Seeing the injury when they took the clingfilm off (D\*\*\*\*). Realising the injury was serious when found out about seriousness of the illness of the kids of other people staying in the R\*\*\*\*\* M\*\*\*\*\* unit . – thinking he might die at O\*\*\*\*\* when people trying to treat him. Worried about him not coming back from operating theatre.

Uncertainty about what was going to happen in hospital/with scar next – trying to work out how much scarring there would be, not sure what % of burns. Worried about infections and healing.

Worries about the future – Worried about when he starts mixing with the kids at school and has swimming lessons.

Pain Knowing that it was painful for John when they scrubbed the skin off (D\*\*\*\*).

Changes in Behaviour Behaviour unusual or worrying – thinking his scream was unusual when it first happened, seeing him not moving and looking a mess (D\*\*\*\*). Him making himself sick and not taking medicines orally – only thing he could do to get back at you (E\*\*\*\*). Losing loads of weight, him waking up screaming when he first got home, him looking dazed and blank on morphine like a loose rag.

Comparing with how child was prior to burn - Having to learn to walk again. Wishing he could be at home playing football like before hospital. Seeing him lose weight.

Feeling other people were judging you as a parent or blaming you – (K\*\*) Nurse saying if it was her child she wouldn't have put flowers in a vase with him because of infection in the water. Feeling told off because you were younger (E\*\*\*\*). Having them talk to your mum instead of you. Having a little old lady say a pray and tell you you'll look after him properly next time. Feeling blamed by M\*\* the ambulance driver testing the water in the bath. Feeling the Russian doctor was questioning you and wanting you to slip up. Worried that D\*\*\*\* might blame you.

Unhelpful or hurtful comments from other people – decorators just standing and staring and not offering to help. Woman being insensitive and giving him a football in hospital.

Watching or being involved in child's treatment – couldn't go to the theatre with him perhaps because had been there when it happened and imagined it being the same (E\*\*\*\*). First time they did the dressings was the hardest (D\*\*\*\*). Watching him take all his medication and have finger pricks (E\*\*\*\*).

Being away from your child at all whilst they were in hospital – didn't even feel like could go for a cup of tea (E\*\*\*\*).

Problems with medical services/staff – Being asked about what happened over and over at O\*\*\*\*, hurting him putting the catheter in, ignoring you when you notice the smell of his infections, not being listened to by doctor about him not taking oral medicines.

**Ways of Coping – This is a list things you did or are doing to try to cope and things you did to manage your feelings, and other things that helped.**

Trying to avoid reminders – not using bathroom where accident happened.

Finding it hard to believe it was happening or serious – thinking will I be back in time for work this afternoon when it happened (E\*\*\*\*). Thinking E\*\*\*\* was being over the top and not thinking it was too serious (D\*\*\*\*).

Going onto auto-pilot – not thinking just wanting to be with him and get on with it (D\*\*\*\*). Just had to cope.

Feeling hopeful there was no or little impact on your child – can't see some of the scars unless you are in the light, can't see scars when he is in T-shirt and shorts and keeps his socks and shoes on. He was too young for it to effect him. He is not doing anything less, still whacking the football.

Doing practical things – put him straight in cool water to calm him down and took his clothes off then went to neighbours house to phone ambulance.

Monitoring medical care and questioning medical staff if necessary – trying to tell nurses about the smell when thought he was infected and own mum insisting that they did some swabs. Stopping doctor giving him medicine orally. Stopping nurse giving him medication too quickly.

Being or getting hopeful – Seeing his injuries getting better and better each time you saw the bandage changes (D\*\*\*\*). Seeing him go from really poorly to much better only 3 weeks later and only needing some skin grafts. Seeing him playing with balloons even though he was completely bandaged. Seeing him suddenly go from not moving to eating a yoghurt and smiling (D\*\*\*\*). Seeing him ill but still a little monkey taking his tube out and entertaining the nurses on the ward. Seeing him kicking a football again. Seeing him walk along at the health visitors. Seeing how much he has come on and him still causing mischief.

Comparing situation with what could have happened/other people who are worse off – meeting a little boy with a mask on his face and thinking at least you can hide John's feet. Meeting A\*\*\*\*\*'s mum whose child had being just as bad and finding out that she had got better.

Being cautious/hopeful about the future – being told that the scars will go lighter but feel you'll just wait and see (D\*\*\*\*). Sometimes think if the children he goes up with don't know any differently about his scars they just think he has always looked the same. Have to wait and see till he goes to school to know how it will effect us in the future.

Coping as a family – D\*\*\*\* trying to be strong for E\*\*\*\* because she was emotional at times and couldn't face the bandage changes. D\*\*\*\* sometimes having to discipline John because he knows that E\*\*\*\* can be soft with him.

Letting other people help/sharing the care with someone else – feeling helped by the lady next door putting John in the sink and locking the house up. Letting D\*\*\*\* take over for a bit when you got to the ward as I had had enough at that point (E\*\*\*\*).

Trying to do best for child after the accident – feeling you want to spoil him sometimes (E\*\*\*\*) and thinking you don't want to be stern with him sometimes when you think he might not have been here.

Making sense of own reactions, what happened, what you needed to do during the accident and what you needed to do when you got home – feeling that you were sometimes emotional but that sometimes there were reasons e.g. not being able to face bandage changes because it was your own child or because you had been with him when the accident happened. Feeling it is important that you try to make him go to bed now because you both need your time as well.

Help and support from family, friends and community – own dad helping with the creaming and mum and dad giving us a break when he was in hospital. Everyone just being strong for us. His child minder H\*\*\* spoiling him.

Support from hospital staff – not telling how long it would take to heal so that we didn't get too upset or telling us the % of burns. Nurses being positive and strong for you.

**Appendix 6 - The analysis process**

- **6a:Index tree 1: Themes following analysis of transcript 1**
- **6b:Index tree 2: Themes following analysis of transcript 1 and reflections**
- **6c:Index tree 3: Themes following analysis of transcripts 1 and 2**
- **6d:Index tree 4: Themes following analysis of transcripts 3 and 4**
- **6e:Index tree 5: Themes following analysis of transcripts 4 to 8**
- **6f: Index tree 6: Themes following analysis of transcripts 8 to 10 and final reflections**

## **Appendix 6a Index tree 1**

### **SUPER-ORDINATE THEME: THREATS TO PARENTAL WELL-BEING DURING EVENT/DURING HOSPITALISATION**

#### **Meaning categories/Sub-themes**

Emotional response (shock, panic, upset/ images/disbelief)

Self-blame/guilt

Helplessness/parenting skills challenged

Reaction of child

Child could die

Fears for the future /stigma

Uncertainty

Response of other family members (partner or non-injured children)

Perceived blame from others

Perceived evaluation by others

Healthcare professionals perceived as failing

Being strong for others

### **SUPER-ORDINATE THEME: THREATS TO PARENTAL WELL-BEING AFTER DISCHARGE /NOW**

#### **Meaning categories/Sub-themes**

Emotional response (distressing recollections/images)

Accident reminders

Self-blame/guilt

Helplessness/parenting skills challenged

Reaction of child

Fears for the future/stigma

Uncertainty

Response of other family members (partner or non-injured children)

Perceived blame from others

Perceived evaluation by others

Healthcare professionals perceived as failing

Safety concerns

### **SUPER-ORDINATE THEME: COPING STRATEGIES DURING EVENT/ DURING HOSPITALISATION**

#### **Meaning categories/Sub-themes**

Cutting off from emotions / “auto-pilot”



Using euphemisms  
Explaining away impact on child

Questioning professionals

Gaining hope from child's "strength"  
Gaining hope from healing signs  
Comparisons with other families who are worse off  
Comparisons of child's pre and post burn functioning  
Comparisons with other families whose children have got better

Being strong for others

Sharing the care or letting others parent  
Support from others offering hope  
Support from family and friends

## **SUPER-ORDINATE THEME: COPING STRATEGIES AFTER DISCHARGE /NOW**

### **Meaning categories/Sub-themes**

Using euphemisms  
Explaining away impact on child  
Avoiding accident reminders/discussions of event

Normalising own reactions  
Normalising child's reactions

Beliefs about ensuring child's safety

Attributing the accident to a unique set of circumstances

Gaining hope from healing signs  
Comparisons with other families who are worse off  
Comparisons of child's pre and post burn functioning  
Comparisons with other families whose children have got better

Gender allocation of roles  
Being strong for others  
Polarised views

Support from family and friends

## **Appendix 6b Index tree 2**

List developed following supervisors' reflections on first transcript.  
 Italicised themes are those that were originally under super-ordinate theme 'Threats to parental well-being after discharge /now' and super-ordinate theme 'Coping strategies after discharge/now'.

### **SUPER-ORDINATE THEME: THREATS TO PARENTS WELL-BEING**

#### **Meaning categories/Sub-themes**

Emotional response (*distressing recollections/ shock, panic, upset/ images/disbelief*)

Self-blame/guilt

Helplessness/parenting skills challenged

Reaction of child

Child could die

Fears for the future /stigma

Uncertainty

Response of other family members (partner or non-injured children)

Perceived blame from others

Perceived evaluation by others

Healthcare professionals perceived as failing

*Safety concerns*

*Accident reminders*

### **SUPER ORDINATE THEME COPING STRATEGIES**

#### **Meaning categories/Sub-themes**

Cutting off from emotions/ "auto-pilot"

Using euphemisms

Explaining away impact on child

*Avoiding accident reminders discussions of event*

Questioning professionals

*Beliefs about ensuring child's safety*

*Normalising child's reactions*

*Normalising own reactions*

*Attributing the accident to a unique set of circumstances*

Gaining hope from child's "strength"

Gaining hope from healing signs

Comparisons with other families who are worse off

Comparisons of child's pre and post burn functioning

Comparisons with other families whose children have got better

*Gender allocation of roles*

Being strong for others\*

*Polarised views*

Sharing the care or letting others parent

Support from others offering hope

Support from family and friends

\* Being strong for others appears to be both a threat and coping strategy

### **Appendix 6c Index tree 3**

Those themes represented in italics are those which emerged following the coding of transcript two or have been moved to a different super-ordinate theme. Sub-ordinate theme headings added to clusters of sub themes are shown in bold.

#### **SUPER-ORDINATE THEME: THREATS TO PARENTS' WELL-BEING**

##### **Emotional responses**

Emotional response (distressing recollections / shock, panic, upset/ images)  
Accident reminders

##### **Self-blame/guilt**

Helplessness/parenting skills challenged

##### **Beliefs about child's injury**

*Appraising child's condition as serious/ injury severe / 'horrible'*

*Changes in child's behaviour/ behaviour unusual* [Two sub-themes originally one theme – child's reaction]

Child could die

Fears for the future/stigma

Uncertainty

*Comparisons of child's pre and post burn functioning* [moved from 'Comparisons as a coping strategy' as appears to be more a form of nostalgic comparison that represents a threat to feeling hopeful about the future]

**Perceptions that accident has had a negative impact on family** [Originally response of other family members (partner or non-injured children)]

##### **Others' responses perceived as threat**

Perceived blame from others

Perceived evaluation by others

Others' comments and reactions unhelpful

Healthcare professionals perceived as failing

Concerns about safety

#### **SUPER-ORDINATE THEME: COPING STRATEGIES**

##### **Distancing self from emotions generated by the accident and its consequences**

Cutting off from emotions/ "auto-pilot"

*Disbelief* [considered adaptive by parents therefore a coping strategy]

Using euphemisms

*Using humour*

Explaining away impact on child

Avoiding accident reminders/discussions of event

**Overcoming difficulties/regaining control***Using practical coping*

Questioning professionals

Beliefs about ensuring child's safety

Normalising child's reactions

**Managing blame/ guilt**

Normalising own reactions

Attributing the accident to a unique set of circumstances

*Making up for accident to child***Maintenance of hope**

Gaining hope from child's "strength"

Gaining hope from healing signs

*Beliefs in recovery**Caution*

Comparisons with other families who are worse off

Comparisons with other families whose children have got better

**Systemic management strategies**

Gender allocation of roles

Being strong for child or partner [Originally being strong for others]\*

Polarised views

**Help and support from others**

Sharing the care or let others parent

Support from others' offering hope

Support from family and friends

*Staff supportive**Staff give information*

\* Being strong for others appears to be appraised as coping strategy overall

### **Appendix 6d Index tree 4**

Those themes represented in italics are those which emerged following the coding of transcripts three and four.

#### **SUPER-ORDINATE THEME: THREATS TO PARENTS' WELL-BEING**

##### **Emotional responses**

Emotional response (distressing recollections / shock, panic, upset/ images)  
Accident reminders

##### **Self-blame/guilt**

Helplessness/parenting skills challenged

##### **Beliefs about child's injury**

Appraising child's condition as serious/ injury severe / 'horrible'  
Changes in child's behaviour/ behaviour unusual  
Child could die  
Fears for the future /stigma  
Uncertainty *re course & outcome* [sub-theme title changed to reflect the fact that uncertainty appeared to be a threat in terms of both what will happen while the child is in hospital, how the injury heals and also when an endpoint or eventual outcome can be defined]  
Comparisons of child's pre and post burn functioning

##### *Observation of child's treatment*

##### **Perceptions that accident has had a negative impact on family**

##### **Others' responses perceived as threat**

Perceived blame from others  
Perceived evaluation by others  
Others' comments and reactions unhelpful  
Healthcare professionals perceived as failing

Concerns about safety

#### **SUPER-ORDINATE THEME: COPING STRATEGIES**

##### **Distancing self from emotions generated by the accident and its consequences**

Cutting off from emotions / "auto-pilot"  
Disbelief  
Using euphemisms  
Using humour  
Explaining away impact on child  
Avoiding accident reminders/discussions of event

##### **Over coming difficulties/regaining control**

Using practical coping

*Beliefs in own resources or developing strengths*

Questioning professionals  
 Beliefs about ensuring child's safety  
*Monitoring child's medical care*

Normalising child's reactions

**Managing blame/guilt**

Normalising own reactions  
 Attributing the accident to a unique set of circumstances  
 Making up for accident to child  
*No one to blame/concluding event was an accident*  
*Avoiding blame discussions* [previously subsumed under 'Avoiding accident reminders / discussions of event' sub-theme. New sub-theme emerge for managing blame]

**Maintenance of hope**

Gaining hope from child's "strength"  
 Gaining hope from healing signs  
 Beliefs in recovery  
 Caution  
*Social Comparison* [sub-themes 'Comparisons with other families who are worse off' and 'Comparisons with other families whose children have got better', merged to form one sub-theme]

**Systemic management strategies**

*Allocation of roles* [changed from 'Gender allocation of roles' as gender not always associated with role allocation]  
 Being strong for child or partner  
 Polarised views

**Help and support from others**

Sharing the care or letting others parent  
 Support from others offering hope  
 Support from family and friends  
 Staff supportive  
 Staff give information  
*Community supportive*

### Appendix 6e Index tree 5

Those themes represented in italics are those which emerged following the coding of transcripts four to eight. Two further super-ordinate theme divisions became apparent at this stage and are underlined.

#### SUPER-ORDINATE THEME: INTRA-PERSONAL THREATS TO PARENTS' WELL-BEING

##### **Emotional responses**

*Struggling with shock, panic, upset* [previously 'Emotional response (distressing recollections / shock, panic, upset / images)' split to form two sub-themes '*Struggling with shock, panic, upset*' and '*Distressing recollections/images*']

*Distressing recollections/ images* [merged with 'Accident reminders' sub-theme as reminders prompt these recollections and images]

##### **Self-blame/guilt**

**Unable to help/doubting care skills** [new sub-ordinate theme heading]

Helplessness/parenting skills challenged

*Perceiving medical knowledge to be inadequate* [separate theme to emerge previously subsumed under Helplessness/parenting skills challenged]

##### **Beliefs about child's injury**

Appraising child's condition as serious/ injury severe / 'horrible'

Child could die

Fears for the future/stigma

Uncertainty re course & outcome

#### SUPER-ORDINATE THEME: INTER-PERSONAL THREATS TO PARENTS' WELL-BEING

**Perception that the accident and its consequences have had a negative impact on child** [New sub-ordinate theme heading]

*Pain* [parents' perceptions of whether the injury had had a negative effect on their child appeared to be clustered around indicators that they were in pain. This emerged as a separate but related sub-theme to whether child's behaviour was unusual or changed at the time of or post injury]

*Comparisons of child's pre and post burn functioning*

*Changes in child's behaviour/ behaviour unusual*

Observation of child's treatment

##### **Perceptions that accident has had a negative impact on family**

##### **Others' responses perceived as threat**

Perceived blame from others

Perceived evaluation by others

Others' comments and reactions unhelpful

Healthcare professionals perceived as failing



Concerns about safety

### **SUPER-ORDINATE THEME: COPING STRATEGIES**

#### **Distancing self from emotions generated by the accident and its consequences**

Cutting off from emotions/ “auto-pilot”

Disbelief

Using euphemisms/*Using humour/avoid emotive language* [themes merged]

Explaining away impact on child

*Normalising child's reactions* [sub-theme moved from ‘Managing blame’ sub-ordinate theme as contents appeared to be strongly related to ‘Explaining away impact on child’]

Avoiding accident reminders/discussions of event

#### **Overcoming difficulties/regaining control**

Using practical coping

Beliefs in own resources or developing strengths

Questioning professionals/*Monitoring child's medical care* [themes merged]

Beliefs about ensuring child’s safety

#### **Making sense of event and reactions [themes below seemed to cluster around a separate sub-ordinate theme]**

*Normalising own reactions*

*Justifying* [new theme to emerge appeared to be related to trying to make sense of own reactions and others]

*Normalising event* [new theme to emerge]

#### **Managing blame/guilt**

Attributing the accident to a unique set of circumstances

Making up for accident to child

No-one to blame/concluding event was an accident

Avoiding blame discussions

#### **Maintenance of hope**

Gaining hope from child’s “strength”

Gaining hope from healing signs

Beliefs in recovery

Caution

Social Comparison

#### **Systemic management strategies**

Allocation of roles

Being strong for child or partner

Polarised views

#### **Help and support from others**

Sharing the care or letting others parent

Support from others offering hope

Support from family and friends

Staff supportive  
Staff give information  
Community supportive

## **Appendix 6f Index tree 6**

Those themes represented in italics are those which emerged following the coding of transcripts eight to ten and following a final examination of all themes.

### **SUPER-ORDINATE THEME 1: INTRA-PERSONAL THREATS TO PARENTAL WELL-BEING**

#### **Emotional responses**

Struggling with shock, panic, upset  
Distressing recollections/ images

#### **Self-blame/guilt**

#### **Unable to help/doubting care skills**

Helplessness/parenting skills challenged  
Perceiving medical knowledge to be inadequate

#### **Beliefs about child's injury**

Appraising child's condition as serious/ injury severe / 'horrible'  
Child could die  
Fears for the future /stigma  
Uncertainty re course & outcome

### **SUPER-ORDINATE THEME 2: INTER-PERSONAL THREATS TO PARENTAL WELL-BEING**

#### **Perception that the accident and its consequences have had a negative impact on child**

Pain  
Comparisons of child's pre and post burn functioning  
Changes in child's behaviour/ behaviour unusual

#### **Perceptions that accident has had a negative impact on family**

#### **Others' responses perceived as threat**

Perceived blame from others  
Perceived evaluation by others  
Others' comments and reactions unhelpful

#### **Healthcare professionals perceived as failing**

### **SUPER-ORDINATE THEME 3: OTHER THREATS TO PARENTAL WELL-BEING**

[collection of threats that are not related to either super-ordinate themes above but were related to distress experienced by parents – largely arising out off specific circumstances or particular situations]

#### **Observation of child's treatment**

*Parental separation from child* [following review of themes emerged as separate subordinate theme as situation that parents found difficult both whilst in hospital with child and afterwards]

### **Concerns about safety**

## **SUPER-ORDINATE THEME 4: COPING STRATEGIES**

### **Distancing self from emotions generated by the accident and its consequences**

Cutting off from emotions/ “auto-pilot”

Disbelief

Using euphemisms/*Using humour/avoid emotive language* [themes merged]

Explaining away impact on child

*Normalising child's reactions* [sub-theme moved from ‘Managing blame’ sub-ordinate theme as contents appeared to be strongly related to ‘Explaining away impact on child’]

Avoiding accident reminders/discussions of event

### **Over coming difficulties/regaining control**

Using practical coping

Beliefs in own resources or developing strengths

Questioning professionals/ *Monitoring child's medical care* [themes merged]

Beliefs about ensuring child's safety

### **Maintenance of hope**

Gaining hope from child's “strength”

Gaining hope from healing signs

Beliefs in recovery

Caution

Social Comparison

### **Managing blame/guilt**

Attributing the accident to a unique set of circumstances

No one to blame/concluding event was an accident

Avoiding blame discussions

*Making up for accident to child*

### **Making sense of event and reactions** [themes below seemed to cluster around a separate subordinate theme]

*Normalising event* [new theme to emerge]

*Normalising own reactions*

*Justifying* [new theme to emerge appeared to be related to trying to make sense of own reactions and others]

### **Systemic management strategies**

Allocation of roles

Being strong for child or partner

Polarised views

### **Help and support from others**

Sharing the care or letting others parent

Support from family and friends [sub-themes merged as contents similar and boundary community and friends not always clear. 'Support from others offering hope' and 'Community support' merged with 'Support of family and friends']

Support from healthcare professionals

Staff supportive

Staff give information

**Appendix 7 – Parents’ and researcher’s reflections on interview and summaries**

- **7a: Parents’ reflections on the interview**
- **7b: Reflections on the research interviews and the research process by the researcher**

**Appendix 7a – Parents’ reflections on the interview**

**F1: John’s family** [Parents identified by staff as coping well. Burns over ten percent TBSA]

*How did you find doing the interview?*

M & F: It was alright / OK.

*When would have been the best time?*

M: Now was a good time - we've got over the worst of it - I think if it had been any earlier closer to the accident, it would not have been a good idea

**F2: Lenny’s family** [Parents identified by staff as somewhat anxious. Burns under ten percent TBSA]

*How did you find doing the interview?*

F: It’s OK, OK. I mean \*\*\*\*\* [the hospital] helped us when we needed the help and if any kind of help we can give then its good. I don't mind giving time to it.

M: Its err good, that err, that this sort of thing is done because anything that can help the situation that was very traumatic, whatever, to a family. Anything that can help \*\*\*\*\* [the hospital] or any other hospital, help that they’re going through, seems good, that's great.

*When would have been the best time?*

F: It's difficult to say really, that you could say earlier, because things were probably fresher in you mind, but then we’re not at the end of it yet and we don't know when the end is. I say life is ups and downs, perhaps if you'd seen us when we came out from seeing the Specialist (recently) and they said 2 years, you know. It was you know Oh (said sounding deflated)

M: It wouldn't have done any harm [earlier] that's for certain.

**F3: Karen’s family** [Mother identified by staff as distressed and having considerable problems managing child’s behaviour. Burns over ten percent TBSA]

*How did you find doing the interview?*

M: No, its OK because you get used to it you know, talking about what's happened err, at the beginning when you tell people what's happened with the burn, its hard, but you get, its like, err (pause) how can I explain, you get used to it you know. Just talking about things and getting it out in the open, I think you know.

*When would have been the best time?*

M: Now is OK. It would have been hard when we first got home as we weren't sure how K\*\*\*\*\* was going to be and it was hard to know if she was OK.

**F4: Robert's family** [Parents identified by staff as coping well. Burns over ten percent TBSA]

*How did you find doing the interview?*

M: I think it helps to talk to someone about it and to talk it through, I don't think we've really ever done this before, never.

F: We've never really sat down and talked about it, you know, it quite in depth isn't it so we've never actually...

M: We've never really discussed about the future or anything. I don't even know whether that's just me being hopeful (laughing). I think at the moment, it's really not a factor at the moment, it's happened but...

*When would have been the best time?*

M: At the very beginning really.

F: After the initial bit but the time to have a talk – this is when is probably about the best time because your mind is more at ease then.

M: And talking it through with somebody who is not involved properly. Somebody who is not your friend or your family so you could sit and talk it all the way through. The social workers talked to us, but that was more about money wasn't it?

F: It's alright doing it as a chat but people will think it's counselling.

I: Because it comes from the psychology service?

F: They'll think, oh it's my fault.

M: If somebody had come to us we'd have felt, oh god do they think it's our fault...

F: There was that thought that did go through your mind.

**F5: Sarah's family** [Parents identified by staff as coping well. Burns under ten percent TBSA]

*How did you find doing the interview?*

M: It hurts talking about it well certain little bits like the footprints on my carpet and things like that stupid little things (upset)

*When would have been the best time?*

M: It doesn't matter ...I did worry when I got the thing through cos I wanted to know why I was getting interviewed I thought someone was blaming me for it cos I turned round to [Husband] and I said look it's finally come they want to come and question me about why she got burnt it did scare me. Well my sister has had two kids took off her so I've always waited for that. It would be a bad time straight after the burn cos my mind was all on the baby. I'd say a month or two months cos the baby is sort of OK then she didn't need that much attention.



**F6: Harriet's family** [Parents identified by staff as anxious. Burns under ten percent TBSA]

*How did you find doing the interview?*

M: Overall it wasn't as bad as I'd expected

*When would have been the best time?*

M: Um ... I would say round about now is probably not a bad time because if it had come too soon after...

D: We can actually say it is starting to get better now

M: It would have been too soon.

M: More in terms of emotion wise like I know I mean. I don't think you would have got a calm response if you know what I mean. It would have just been .I mean if you had come in the first couple of months while she was still having all the bandages then we didn't know how she was going to be, we wouldn't have know any different, I mean we might be a bit more aware than what we are now because she, the baby has changed so much in 12 months as to how it affected her and whatever but then would have just been short term differences anyway cos now she is back.

**F7: Elizabeth's family** [Mother identified by staff as anxious. Burns over ten percent TBSA]

*How did you find doing the interview?*

M: OK.

*When would have been the best time?*

M: No about now, it wouldn't have mattered a few months ago but really soon afterwards wouldn't have been. The first 4-5 months I couldn't talk about it without getting upset. But as time goes by you do, you do think about it, I have to apply her cream everyday so its always there for me but I don't think about how it felt at the time. I was just reading a novel yesterday about some woman who resented her little girl ... this child played by the teapot, and you knew what was going to happen, she was going to pull the teapot, I'm talking about in the 30's, going to scald herself. But as it was happening I just wanted to shut the book, I didn't want to read it, I thought, I know what is going to happen.

M: It would have been helpful at the time if there had been somewhere or someone to turn to, to talk to. Even if it had been a counsellor or anybody we felt it would have been good then to talk to somebody. It could have allayed our fears because the nurses don't have time and they're not there for that. As it was all happening. Because I think the emotions are much more heightened at the time anyway, the guilt, the feeling of helplessness and everything. They are there at the time and some form of help group or something. But even if a phone number was given to you, so that if you needed to talk ring that number. I would have found it helpful at the time.

**F8: Toby's family** [Parents identified as coping well. Burns under ten percent TBSA]

*How did you find doing the interview?*

M: Good actually, it was good.

F: Yes, like you order your thoughts about it.

M: It's kind of like making you aware of...

F: Stuff that you hadn't really thought about.

M: I'm still very much aware of the feelings that I had then, which were very strong and you know, just recalling it, they come up again. So it was good really to look at it again, because you just get on with things and leave them so it was good.

*When would have been the best time?*

M: I don't think I'd have wanted it then.

F: Yes (pause) you know, would have been too confused I think.

M: I think I would have been too upset. I think it has been OK because Tommy is OK. I think myself if he had needed further treatment or if there was any concern about the future I don't think I could have done...

M: I think it would have been good to have had something like this straight after leaving hospital. That would have felt quite good, just to have had a chance and an opportunity to off-load I think.

F: That's too soon. But again I suppose it depends on the injury, if you get something that is ongoing and required lots more visits, being harder to say whether it's a good time, or like in our situation that it was all finished.

**F9: James' family** [Parents identified as not coping. Burns over ten percent TBSA]

*How did you find doing the interview? When would have been the best time?*

M: OK I think if you were going to do an interview like this, if I was going to do an interview like this I would interview ... The problem is, is that if you want to interview people during just after, that kind of thing, that's a real touchy area isn't it, you've got to be really careful, because people are really sensitive and everything's just blown up. Probably say no, you're not interviewing me. But ideally it would be around then, then maybe a few months ahead like we are.

**F10: Kevin's family** [Parents identified as coping well. Burns under ten percent TBSA]

*How did you find doing the interview? When would have been the best time?*

M: No, its probably a good time actually. I think now is probably a good time, yes, now is a good time when you can see all the bits of the jigsaw so to speak. Yes, because you've been through the shock, you've been through the hospital treatment, you've been through the follow-up treatment. I know that I've got another 18 months to go but it's a small price to pay.

## Appendix 7b - Reflections on the research interviews and the research process by the researcher

### 1: Reflections on the research interviews by the researcher

The diary in this appendix summarises the notes and thoughts of the researcher following interviews. It also notes parents' reflections on the individualised summary of the interview analysis that they received when they were contacted for a second time. The researchers reflections on the research process as a whole, including her preconceptions, are also discussed.

**F1: John's parents** [Parents identified by staff as coping well. Burns over ten percent TBSA and fluid resuscitation required]

Both parents discussed how young they had felt to have gone through such an experience. Appeared keen to display maturity to interviewer. John's mother dominated the interview. She made many criticisms of the service she received and gave detailed explanation of her own role whilst her child was in hospital. Was this an opportunity for her to combat the helplessness she initially felt or did she criticise staff whilst she was at the hospital? I wondered how staff had appraised her reaction. Seemed to describe accident circumstances in minute detail and corrects self. Does she view me as part of the hospital and scrutinising this account? Felt John's father was close to tears when describing accident circumstances but for the rest of the interview appeared detached and quite numb at times preferring to let partner speak. He only interjected to minimise any service criticisms suggested by his partner or to emphasise aspects of child's rehabilitation that had yet to be obtained. Interview difficult to guide as mother often strayed from question. How did others respond to this? Did they try to take control? Mother appears to be very supportive of father during interview (puts hand out to support him when he describes his nightmares). This contrary to reports offered by parents of the roles they allocated themselves whilst in hospital. I wondered how welcome the role allocation had been for the father (always being present during painful procedures) and the extent to which he received support as he didn't stay at the hospital for long. Also how acceptable was it to the couple and family to show weakness – were there family pressures for them to prove they could cope after having child at a young age. Are the parents concerned that I won't believe them or feel that I blame them or think they're too young? Father does not disagree with mother when she discusses blaming herself or feeling guilty.

Unable to contact for verification of summary.

**F2: Lenny's parents** [Parents identified by staff as somewhat anxious. Burns under ten percent TBSA ]

Mother described her dread of her husband's reaction regarding the burn. I initially became concerned that this woman's ability to cope was being hindered by her husband's reaction and was nervous about asking some interview questions. Father describes themselves as a very close family who don't need others. Does this mean it would be difficult for staff to offer appropriate support? Or does it represent strength? However as she spoke quite openly about his temper and 'over the top' reactions, and did not appear to be at all nervous, I began to feel that I was more anxious about this than she was. How is this encounter reflective of her encounters with others in general? Does she always take on a victim role? How does this impact upon the support offered? I wondered if this was the family's or her way of getting further support given her husbands' apparent aggressiveness. Her apparent vulnerability and at times deference to others, and her

descriptions of her difficulties coping whilst at the hospital were at odds with her stories regarding her help with her child's treatment and discovering her own resources. Is this a role she adopts in relation to her husband? Again mother offered detailed description of accident circumstances and appeared anxious and upset while doing so? Does she feel I'm evaluating her account or is recollection of the events distressing?

Both parents agreed with summary overall. Stated that their only concern was that the change in his behaviour when he was initially in hospital did not persist for long. This was fed back into the analysis. Was this another example of explaining away influence on child?

**F3: Karen's family** [Mother identified by staff as distressed and having considerable problems managing child's behaviour. Burns over ten percent TBSA]

Mother only present for interview. Father looking after children in kitchen although invited to join in. Is this considered to be her story because she was in the house at the time of the accident? This mother is bilingual but I was sometimes unsure whether she understood the question or whether the topic area was too emotional to discuss. Her description of the accident circumstances stood out from the rest of the interview in terms of clarity – had she had to tell this story before? On listening to the tape of the interview it became more apparent that she found the more emotional aspects of her story difficult to describe during the interview. After the tape was switched off and when the interview was arranged by 'phone, she described her experiences as extremely difficult and emotionally draining and she had only recently (6 months after the accident) started to feel better. Why does she not want this to be recorded? Does she feel it is important to present a coping front? She describes wanting support to manage her child's behaviour problems. Do health care professional take these requests seriously? This mother seemed grateful to be offered the opportunity to take part. Did she have difficulty accessing similar support in hospital? Felt drawn to ensure that she had considered help for herself. She had appeared to be quite cut off from her emotions. Did her coping strategies, include distancing herself from the difficulties? Despite time since accident, child's behaviour problems since accident seemed to make this difficult. Is her guilt regarding the accident making it difficult for to manage her child's behaviour? Observed children's father managing behaviour successfully.

Mother agreed with summary and reiterated the fact that she wished to help other parents through taking part in research.

**F4: Robert's family** [Parents identified by staff as coping well. Burns over ten percent TBSA]

Mother present for all of interview, father joined the interview half-way through. Both presented similar stories although the father noted that he had not discussed his experiences in such depth before as it was not his accustomed way of coping. I wondered what impact the interview had on him. Both described finding it OK but reflected that although it was now in the past it was still at the back of their minds. Mother became very upset at recollection of event and stated that whilst she had discussed the event with her family not long after it happened, she had not really discussed it since. Mother indicated safety precautions that had been taken around the house since the accident.

Both parents agreed with summary of interview although mother stated that it all felt very much in the past now. Mother suggested that since the interview she felt she had become less conscious of hiding the scars on Robert's arms for 'photos suggesting that adjustment still an ongoing process.

**F5: Sarah's family** [Parents identified by staff as coping well. Burns under ten percent TBSA]

Mother only present at interview and said she felt her husband would not have said anything and was not keen to be there. Later said that this was her husband's way of coping. I wondered how she had been able to get support. Mother cried throughout interview. Initially answered questions with one or two words and needed much encouragement. This made me feel I was being too invasive and I was therefore cautious about probing more deeply. However having told me she thought that the reason she was being interviewed was because she was being investigated. I tried to reassure her and she relaxed somewhat. I wonder how this affected her approach to hospital staff? This woman appeared to be extremely vulnerable but said she got very little support and did not want to go outside the family for it as she felt it was important to cope by herself. I wondered what impact the interview may have on her.

At second contact 'phone call, she said she felt that she had begun to feel more sure that her child was not effected by the injury and that she had felt more confident that her other children would be OK to play outside again although she still felt unable to be separated from Sarah at all. She also said that she felt that she was more confident in the fact that she was a good mother. However, still avoided reminders such as the fireplace and still described becoming extremely anxious at sudden noises upstairs thinking a child had hurt themselves and was still vigilant for signs that Sarah "remembered" the accident. Suggestive that adjustment to accident still an ongoing process. Overall agreed with summary of interview analysis.

**F6: Harriet's family** [Parents identified by staff as anxious. Burns under ten percent TBSA]

Mother described her experiences as having been very stressful on the 'phone and sounded anxious but said she was keen to help other parents. At interview appeared to describe her experiences in quite non-emotive terms, used humour and suggested this was a common strategy in her family. Husband did not say much – was this because he was not present at the time of the accident? Was this her story only? Both said they preferred not discuss the event as they did not want to allocate blame – this was at odds with them volunteering to be interviewed. Had blame been allocated anyway? Mother described the interview as not as bad as she had anticipated. Did she mean she felt that she had been able to control her emotions?

Agreed with the interview summary and stated that the event was not something they thought about anymore. However, went on to discuss fact that child had been fitted for new pressure garment (at interview had expressed concern that this is good as the scar is going to get) and that they felt that they felt the scar was still improving. Previously had not expected to have a new pressure garment. Did the new pressure garment serve to maintain hope?

**F7: Elizabeth's family** [Mother identified by staff as anxious. Burns over ten percent TBSA]

Extremely difficult to interrupt this mother – need little prompting to answer questions. Felt the interview was very much controlled by the mother and I wondered if this reflected her approach towards hospital staff and how they would interpret it? Used lots of medical terminology and appeared keen to demonstrate her knowledge to me. Did this also help her cope? Was this an important way for her to cope with emotions generated by the interview? She did not appear to be distressed even when describing quite difficult experiences. Sometimes seemed as if she was talking about somebody else. Was this another way of coping or was she just less distressed by the recollections than others had been? It seemed very important for this mother to have been

strong and cope in comparison to other parents. This mother also appeared to contradict and then correct herself about how the injury occurred and how she responded.

Agreed with overall interview summary, except for stating that she felt that she had been too diplomatic about her husband's role during the burn accident and after it had occurred. She felt he had in fact forced her into being in a coping role as he did not wish to be involved and only came to the hospital infrequently and then only when he was sure his daughter would be asleep. Also discussed concerns about injury scar on her child's chest as her child currently had chicken pox although she had played down these worries at the first interview. Did she feel less able to explain away her child's scars when faced with other threats to coping such as worries about her child's current illness?

**F8: Toby's family** [Parents identified as coping well. Burns under ten percent TBSA]

Both parents keen to be interviewed. Mother stated she felt particularly interested as she worked part time as counsellor and felt it was an important process for both her and her partner. Mother extremely emotionally articulate, father less so. Had he felt able to voice his concerns after the accident? Was this a common pattern for this family? Parents keen to receive analysis summary. Pedantic in descriptions of event especially in describing what they felt they did wrong in terms of first aid – e.g. taking their child's clothes off before putting them in the bath of cold water. Did they feel I was evaluating them because I was from the hospital?

Unable to contact parents for discussion of interview summary.

**F9: James' family** [Parents identified as not coping Burns over ten percent TBSA]

Mother only present. Stated she was keen to help me as student. Interview extremely long as mother keen to explain situations in detail and had kept notes of different medical events that had occurred. I wondered whether this had offered her some control over events as it was at odds with her descriptions of her role in helping her child – she described feeling uncertain. Told me that as a psychology graduate she had certain ideas about how she would have carried out the research. Was this a way of addressing the vulnerability she felt? (She became quite upset during the interview). Role of wider family important to this woman with lots of others involved in child's care and lots of arguments over appropriate care for child. How was this appraised by hospital staff? Distressed when discussing comments they had made about her parenting abilities. I wondered how this and the burn injury had impacted upon her feelings about parenting? I sometimes felt that the interview strayed more on to the difficulties with family arguments than concentrating on her feelings about events. She was highly critical of services and I wondered how she would reflect on my interpretations of the interview.

Mother agreed with overall summary and stated that she had found that interview had taken some of the weight off her and was helpful.

**F10: Kevin's family** [Parents identified as coping well. Burns under ten percent TBSA]

Mother only present. Appeared distressed and near tears on several occasions through out interview and cried at recollection of observing child's treatment. Stated she had only recently begun to discuss her experiences and had recently been referred to a family counsellor who she had not felt was interested in her story. Wondered whether she felt this about me/other

professionals? Did this prevent her from saying what she really felt? Described herself as a copier and when the tape was switched off (after she became upset) and described how difficult it was for her to tolerate the feeling of not being able to cope. I felt challenged to offer help but she felt that she had recently received appropriate help from her health visitor and that this was useful as the health visitor did not question her parenting and seemed more keen to help her. Used lots of medical terminology confidently and described her experiences in a precise manner at the same time as appearing to be distressed. Was this reflective of a need to take control/redress the power balance?

At second contact she stated that she had found the interview helpful as she felt she had got “a lot of things out”.

## **2 :Reflections on the research process**

### *‘Bracketing’ preconceptions*

The researcher considered the topic to be a sensitive area having discussed the impact injuries and illness diagnoses had on other people’s children. Responses from parents seemed to vary from ‘just getting on with it’ to becoming more careful but trying not to limit their children’s natural curiosity. Guilt seemed to be a more of a feature of parents’ reactions to injuries to their children if their children were under two. The researcher felt that the parents might experience aspects of their child’s hospitalisation challenging if they were not confident to ask questions of medical staff or ask for reassurance. She also wondered whether parents whose children were in and out of hospital more often, got used to these experiences compared to those who had only been admitted after the initial event.

The researchers clinical and previous research experience led her to believe that parents of children with physical or learning disabilities diagnosed at birth were constantly re-adjusting to their child’s condition at the same time as under playing its importance in their lives. The researcher also felt that some parents worked hard to make the best of their own and their children’s experiences with disability.

Researcher wondered whether as a psychologist she may be inadvertently searching for contextual factors that may place people’s mental health at risk and also commonly identified coping strategies, such as social support, as one would when formulating a clinical case for psychological intervention.

### *Interviews and recruitment*

Responding to parents distress whilst endeavouring to remain objective was helped by discussing interviews in supervision and recognising that reminders of the accident were distressing for parents. Sometimes this meant that the interviews took longer than expected. The researcher felt it was important to be as relaxed and respectful of parents styles of responding to the interview situation, especially as the interview was in their home and as some already appeared to be anxious about the prospect of being interviewed.

Recruitment proved to be challenging at times as it required a considerable amount of staff time in order that they could reach consensus viewpoints but also in order to identify parents that met the selection criteria and sampling strategy requirements. It was especially difficult to ensure participant confidentiality as parents were being selected from a limited pool. This meant that it became even more important to ensure that quotes from the transcripts did not identify parents in anyway. Staff members were clearly interested in the research findings and again it proved challenging not to disclose any thing other than general feedback whilst encouraging them to continue to engage in the recruitment process. Recruiting through the Doctors, proved difficult as those who were most likely to remember their impressions of parents that were also recalled by nurses and not necessarily in the notes, were often more junior staff members who were only associated with the ward for a short period of time. Having tried a number of different methods to recruit a sample that varied along the pre-determined dimensions and met the quota targets, it was decided to halt recruitment. It was felt that sufficient attempts had been made at obtaining a varied sample within the constraints of patient confidentiality and the pragmatics associated with recruitment.