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LIVERPOOL

Parental Adjustment Following Paediatric Burn Injury

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18th September 2017

Submitted in partial fulfilment of the Doctorate in Clinical Psychology

University of Liverpool

Acknowledgements

I would like say a huge thank you to the children and parents of Alder Hey Children's Hospital who gave their time to participate in the study. It was a privilege to hear your stories and follow your recovery journeys. Many thanks to the nurses on the burn unit, especially the regulars at outpatient clinics. You were so welcoming and supportive of the study.

I am incredibly grateful to my three supervisors for their invaluable guidance at each stage in the process. Peter Taylor and Natalie Holman – thank you for helping me to get the project off the ground – and a big thanks to Luna Centifanti for jumping on board in year 3 and taking over from Peter. I would also like to thank Jessica Stephenson for her help with recruitment and quality assessing papers, and Robin Coakley for being my second reviewer for the data selection stages of the systematic review.

Lastly, a special thanks to my friends and family for being my anchor and support over the last three years. In particular, my 'yndlings person' and expert proof reader, David, but also my 'come dine' girls, Annie and Elizabeth, and my mum and dad – I could not have done it without you all.

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Thesis Overview

Every year in the UK and Wales, 3 750 children (aged 15 years or under) are seen in accident and emergency departments following a burn injury (Child Accident Prevention Trust [CAPT], 2012). Around 95% of injuries occur at home and are predominantly the result of everyday situations, such as a scald from a hot drink or contact with electrical appliances (CAPT, 2012). Burn injuries can involve long-lasting painful and physical consequences for the child (e.g. skin grafts, rehabilitation and permanent scarring). However, the psychological impact of an injury is not limited to the child affected. Indeed, parents are often more emotionally distressed than the children themselves (Kent, King, & Cochrane, 2000).

This thesis will focus on the psychological adjustment of parents following their child's burn injury. Previous research has indicated that parents experience elevated levels of distress. For instance, 50% of parents whose child required an inpatient admission met clinical criteria for traumatic stress (Bakker, Van der Heijden, Van Son, & Van Loey, 2013). High rates of depression and anxiety have also been reported (Phillips & Rumsey, 2008). In addition, parent's post-burn adjustment has direct implications for their child's emotion and physical recovery (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). Research can therefore play an important role in identifying factors that are associated with this adjustment process. Such findings could inform clinical practices, for instance, in providing better identification and support of families who may be struggling. To this end, the thesis will examine what puts families at risk of poor adjustment and what protects against this.

The thesis takes the form of two chapters: a systematic review and an empirical paper. In the systematic review, a search of the literature was undertaken to identify all factors associated with adjustment. Poor adjustment was operationalised as the experience of symptoms of depression, anxiety and post-traumatic stress disorder. The findings were

synthesised using a narrative approach. Overall it was found that objective injury characteristics (e.g. burn size) were poor predictors for parent's adjustment. Instead subjective appraisals of the burn event, parent's pre-existing difficulties, the child's symptoms of PTSD and systemic factors were all robustly associated with parents' distress.

The empirical paper investigated the impact of subjective factors: guilt and shame and self-compassion on parental adjustment. The study expanded previous findings that guilt is a common experience among parents of children who have sustained a burn injury (Mason, 1993). For example, it used a validated measure of guilt to examine this complex emotion and is the first to consider the related construct of shame. A sample of parents was recruited at a regional children's burn unit (Alder Hey Children's Hospital, Liverpool) during the acute phase following their child's burn injury. Guilt, shame and self-compassion were found to be good predictors for adjustment in parents, while objective characteristics of the burn injury were less important. Furthermore this study contributed to the growing body of evidence that guilt and shame represent distinct constructs and are differentially associated with psychological outcomes (Kim, Thibodeau, & Jorgensen, 2011).

Overall these two papers integrate and extend our current understanding of parental adjustment in the context of paediatric burn injuries. Both papers offer a number of clinical recommendations which may help to improve patient care.

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Chapter 1: Systematic Literature Review

A Systematic Review of the Factors Affecting Psychological Adjustment of Parents Following Paediatric Burn Injury

Laura Hawkins

Abstract

Background: High levels of distress have been reported in parents of children who have sustained a burn injury. Poor adjustment in parents can also impact on their child's physical and emotional outcomes. It is therefore important to identify factors which put some families at risk of experiencing difficulties post-injury.

Objectives: To examine the risk and protective factors associated with psychological adjustment in parents following paediatric burn injuries. Poor adjustment was operationalised as the experience of symptoms of traumatic stress, depression and anxiety.

Method: A systematic search was carried out using three databases: MEDLINE, PsychINFO and CINAHL Plus. A total of 19 articles were identified that met the inclusion criteria for the review. The articles were quality assessed and a narrative synthesis of findings was completed.

Results: Parental adjustment was robustly associated with the following: subjective factors (e.g. parent's feelings and appraisals about the burn event); pre-existing factors (e.g. a history of mental health difficulties); child PTSD symptoms; and social support. In contrast, objective characteristics of the burn injury (e.g. size of burn) and demographic factors (e.g. age and gender) of the child and parent inconsistently predicted adjustment in parents.

Conclusions: Burns units can improve child and family outcomes by attending to the subjective injury experience and through improving parental support. Screening and intervention for psychological difficulties should be offered to all families regardless of the size and severity of the burn injury.

Keywords: Burn injury, parents, children, PTSD, depression, anxiety

Introduction

A burn injury is an incredibly stressful experience for both the injured child and their parents (Rizzone, Stoddard, Murphy, & Kruger, 1994). The burn event itself may evoke fear, helplessness and there may be a perceived life-threat to the child (Kazak et al., 2006). In the acute phase following the accident, children and their families experience hospitalisation, numerous painful medical procedures, and uncertainty about long-lasting scarring and disfigurement (Bakker, Van Loey, Van Son, & Van der Heijden, 2010). Parents are often psychologically more affected by the event than the children themselves (Fukunishi, 1998) and are at increased risk of developing psychological difficulties.

In the first three months following a burn injury, around half of parents meet clinical criteria for traumatic stress (Hall et al., 2006). Anxiety and depression are also common: 69% of inpatient and 33% of outpatient parents experienced clinically significant anxiety, while 44% and 22% of parents met criteria for depression as inpatients and outpatients respectively (Phillips & Rumsey, 2008). For a subset of parents these difficulties can become long-term: Bakker et al. (2010) reported post-traumatic stress symptoms in mothers as long as 10 years after their child's burn accident. Heightened levels of distress are therefore common experiences among parents, which may impact on coping and adaptation to the injury.

Parental adjustment has direct implications for the recovering child. For example, parents have reported feeling less able to adopt a responsive parenting style and attend to the needs of their child when they themselves feel distressed (Alisic, Boeije, Jongmans, & Kleber, 2012). Distressed parents may also struggle to manage the treatment demands following the burn injury (Price et al., 2016), such as attending appointments and the burn aftercare regimen (e.g. massaging the scar tissue daily). Furthermore, poor parental adjustment has consistently been identified as both a risk and maintenance factor for child

emotional and behavioural problems post-injury (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). Thus, parental distress can impact their child's recovery, both psychologically and physically.

Kazak's model of Paediatric Medical Traumatic Stress (PMTS) (Kazak et al., 2006; Price et al., 2016) may help us to understand parental responses to paediatric burn injuries. Drawing on a large body of evidence from a range of paediatric injuries and illnesses, the PMTS model provides a conceptual framework for understanding the adjustment process of a child and their family following a medical event. Further, Kazak and colleagues (2006) draw some useful conclusions about the risk and protective factors associated with poor adjustment. It is suggested that these factors may aid health care professionals to better identify and support families who are struggling.

One of the most powerful predictors of adjustment in Kazak and colleagues' (2006) paper was the subjective experience of an injury/illness. Evidence was provided that objective characteristics of the medical event (such as its complexity and severity) are often poorly associated with adjustment. Instead, subjective factors (for example, the parent's own feelings and beliefs about the burn injury) are found to be more important. This fits with the burns literature whereby the size and severity of the burn is inconsistently associated with psychological distress (e.g. Rizzone et al., 1994) with many studies finding no such relationship (e.g. Cella, Perry, Poag, & Amand, 1998). In addition, Kazak et al. (2006) propose that psychological adjustment is relatively stable over time. Therefore parents who are most distressed during the acute phase immediately following an injury or diagnosis also show the greatest risk of long-term difficulties. Finally, Kazak et al. (2006) suggest that poor adjustment is strongly related to pre-existing factors. Thus a parent with mental health problems or a history of trauma is much more likely to experience difficulties, if their child was to sustain an injury.

Knowing which families would benefit from more help following a burn injury might help to reduce distress that leads to poor coping and adjustment. Therefore, research that identifies risk and protective factors is vital in order that medical teams can provide better support to families. However, to date only two reviews have been conducted in the area of paediatric burn injuries (Tarnowski, Rasnake, Gavaghan-Jones, & Smith, 1991; Bakker, Maertens, Van Son, & Van Loey, 2013a). These have been broad ranging and mainly focused on the experience of the child, whilst only incidentally touching on the effect of the burn injury on the rest of the family. This reflects the proportion of research conducted in this area which is heavily weighted towards child outcomes, although we know these are heavily influenced by the parent (e.g. De Young et al., 2014). Since the last systematic search of the literature by Bakker, Maertens et al. (2013) in December 2011, a number of important articles have been published on parental adjustment (e.g. McGarry et al., 2013; Willebrand & Sveen, 2016a, b). These provide a significant contribution to our understanding of the parental response to paediatric burn injuries and the pattern of factors associated with this process.

Aims

The aim of this review is therefore to provide a comprehensive and updated synthesis of the literature on parents' psychological adjustment to their child's burn injury. In particular, the review will consider the risk and protective factors for adjustment in parents following paediatric burn injury. These will be examined with reference to Kazak and colleagues' (2006) PMTS model.

Methods

Prior to undertaking the review, a protocol was submitted for registration on the Prospero register (www.crd.york.ac.uk/PROSPERO/). Registration number: CRD42016046059.

Eligibility Criteria

Studies were included in the review if they met the following criteria: 1) participants were parents or primary caregivers whose child (aged 18 years or younger) had sustained an accidental burn injury; 2) the studies measured the parents' psychological adjustment to the injury; and 3) measured factors associated with parental adjustment. Poor adjustment was operationalised as the experience of symptoms of traumatic stress, depression and anxiety. Only studies where the mean age of the children was 18 years or younger were included in the review. For studies where no mean age was reported, the upper limit of the age range had to be 18 or below. Studies were excluded if the sample included burn injuries that were non-accidental. Where parental adjustment was only measured but as an independent variable for another factor (such as child adjustment), this type of study was also excluded. Only quantitative studies were included in the review. However the following study designs were all accepted: cross-sectional, longitudinal, case-control and where intervention studies consisted of a control that provided useable data. Articles that were not written in English were excluded.

Information Sources

Searches were carried out using three databases: MEDLINE (1948-current), PsychINFO (1887-current) and CINAHL Plus (1937-current). These databases were selected as they yielded the most results for the search terms below. The last search was carried out on 9th November 2016. The reference lists of all included papers were then checked for

additional articles that might meet the review's inclusion criteria. The authors of the included papers were also contacted (30th November 2016) with regards to related papers or unpublished work. Attempts to identify grey literature was made by searching the EThoS and ProQuest databases using the below search terms. In addition, the conference abstracts from the annual meetings (2000-2015) of the American Burn Associations were screened for potential eligible research. The British Burn Association's website was also checked but no conference abstracts were identified.

Search Strategy

A keyword search was undertaken using the search items: (Injur* OR burn* OR scald) AND (child* OR pediatric OR paediatric OR adolesc* OR infant) AND (parent* OR caregiver OR mother OR father OR family) AND (anx* OR depress* OR distress OR "post-traumatic stress" OR PTSD OR "acute stress" OR ASD).

To ensure that all relevant articles had been identified, a controlled vocabulary search (e.g. MeSH headings) was also carried out. This is in line with the Cochrane Collaboration guidelines (Higgins & Green, 2011). Different controlled vocabulary terms were identified for the three databases. These can be viewed in Appendix A.

Data Selection

All references generated in the search were exported into a reference management software (Mendeley) and duplicates were removed. The author screened the titles and abstracts of all studies for eligibility. To help control for reliability, a second researcher screened a sample of 10% of the articles. The remaining articles were subsequently read independently in full by the two researchers. Where there was disagreement about whether an article met the inclusion criteria for the review, the article was discussed and the researchers

came to a joint conclusion. The agreement between the researchers was 99.33% for the titles and abstracts, and 86.67% for the full articles. The process of data selection can be viewed in the flowchart in Figure 1

Risk of Bias

All included papers were quality assessed using the QATSDD tool (Sirriyeh, Lawton, Gardner, & Armitage, 2012) by two researchers independently. This is a standardised measure that has been shown to have good face validity and inter-rater reliability for quality assessing articles (Sirriyeh et al., 2012). It consists of 14 items (for quantitative articles) that are rated on a 4-point scale. The researchers discussed discrepancies in their ratings and came to an overall consensus for each paper. These results can be viewed in Appendix B.

Data Extraction and Synthesis

A data extraction form was generated for the purpose of the review. This was first piloted and subsequently used by the author to extract the following data. Study characteristics: study design, country of origin, sample characteristics, child characteristics, burn size (Total Body Surface Area [TBSA]), causes of the burn injury, timespan since burn injury/evaluation moments. Study outcomes: outcome measures, analysis, findings.

A narrative approach was used for the synthesis of findings. This method was chosen because the included studies differed in study design, while some failed to report effect sizes. For these reasons a meta-analysis would have been unsuitable (Ryan, 2013). The analysis focused exclusively on the studies' outcomes rather than the authors' interpretation of the findings.

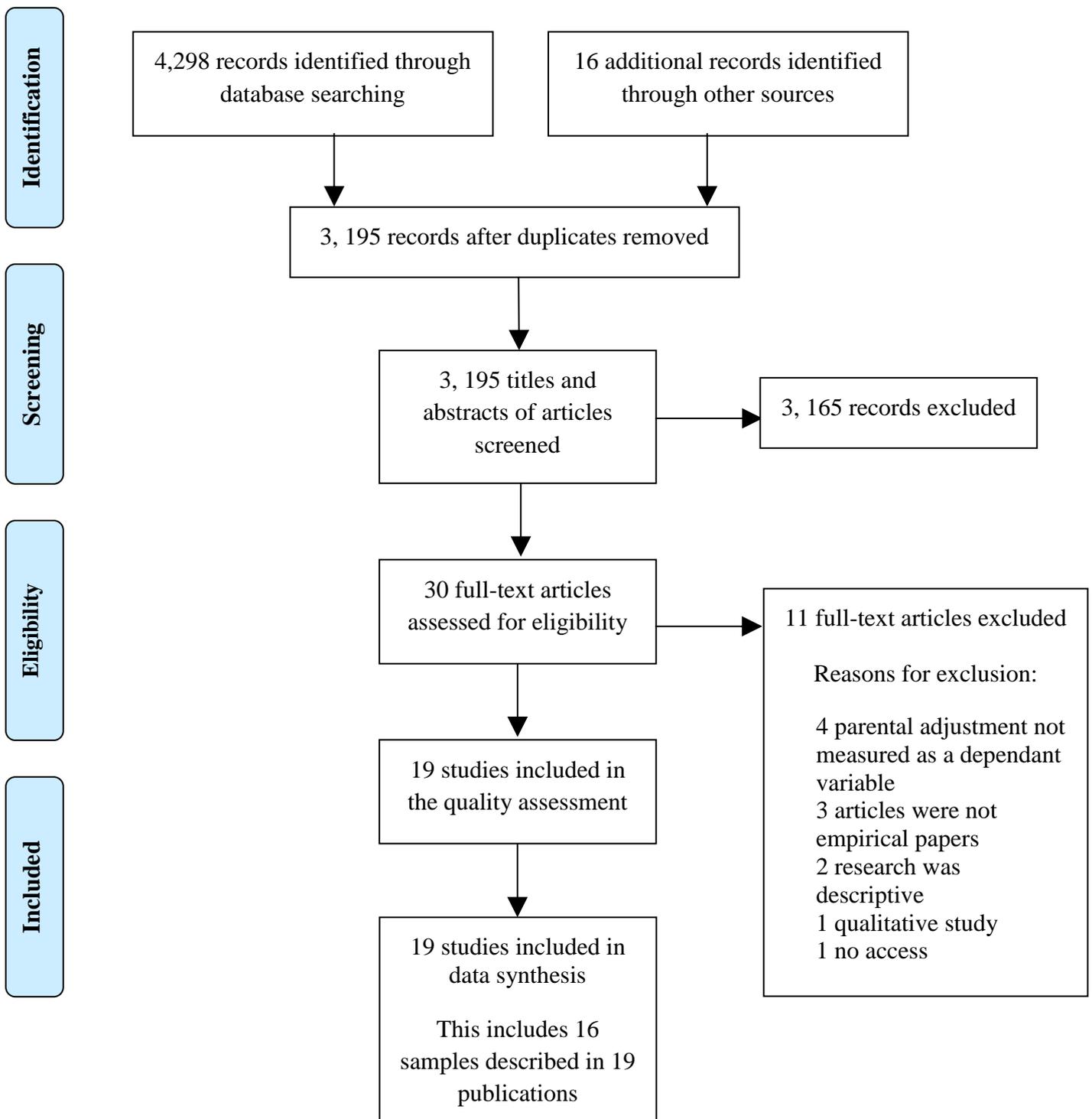


Figure 1. Flow chart of the selection process of the included studies (adapted from Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009)

Results

A total of 4,298 results were generated in the database search. A further 16 results were identified from screening the reference lists of papers included in the final selection, conference abstracts and searching EThoS and ProQuest. Following the removal of duplicates, this total was reduced to 3,195 results. A further 3,165 results were excluded after the titles and abstracts of these articles were screened for suitability. This left 30 articles which were then read in full. Of these articles, 19 were included in the review while 11 were excluded. The reasons for exclusion were: parental adjustment was not measured as a dependent variable (N = 4); article was not an empirical paper (N = 3); research was descriptive (N = 2); qualitative methodology (N = 1); and no access to the paper (N = 1). This can be viewed in Figure 1.

The total of 19 papers relates to 16 independent samples. This is because, in three instances, a sample was described in more than one paper. For the two papers by Rivlin and Faragher (2007a, b) the study design and sample characteristics were the same for both papers. These two papers will therefore be reported together in the study characteristics and outcome tables (see Tables 1 and 2). As the sample characteristics differed in the two papers by Bakker and colleagues (Bakker, Van der Heijden, Van Son, & Van Loey, 2012, 2013), and Willebrand and Sveen (2016a, b), these papers are described separately

Study Characteristics

Characteristics of the included studies can be seen in Table 1. The majority of studies used a cross-sectional design (N = 12) while the remaining six were longitudinal. For six studies the sample included just mothers. Where studies included both mothers and fathers, in most cases there was a significant underrepresentation of fathers. The exception was the sample described by Bakker, Van der Heijden et al. (2012, 2013) where the ratio was more

evenly weighted. For three papers (Bakker, Van der Heijden et al. 2012, 2013; McGarry et al., 2013) both parents of a child participated in some cases. Almost universally studies reported that more boys were burnt than girls. The exception was Rivlin and Faragher's (2007a, b) but the even gender split in this paper was the result of a stratified sample. Overall there was huge variation in age ranges of children that were studied. With regards to burn size, all but one study (Odar et al., 2013) had samples of children who had sustained a wide range of injuries including those classified as having a 'major' burn injury (TBSA >10%) (American Burn Association, 1990). Across studies scalds were the most common cause of the injury. One exception was El Hamaoui, Yaalaoui, Chihabeddine, Boukind and Moussaoui (2006) who reported an unusually high rate of flame burns (80%). This difference might relate to cultural factors as this study was the only one conducted in Morocco, and one of only two not from a Western culture. The studies varied in the timespan since the injury: 10 studies recruited participants in the acute phase following the injury (< four weeks) while 10 recruited participants many years after the injury. Two studies included samples of both acute and recovering participants (> six months) (Blakeney et al., 1993; Phillips & Rumsey, 2008).

Table 1

Study Characteristics

Author (Year)	Study design	Country	Sample	Child gender	Child age (range and mean)	Bum TBSA	Causes of injury	Evaluation moments (time since injury)
Bakker et al. (2010)	Longitudinal	Netherlands	48 mothers	58% boys	0–13 yrs <i>M</i> 3 yrs	Nodata	Scalds (73%), flame (17%), other (10%)	1 yr, 2 yrs, 11 yrs
Bakker et al. (2012)*	Cross-sectional	Netherlands and Belgium	182 mothers and 154 fathers (143 couples)	65% boys	0–4 yrs <i>M</i> 1.8 yrs	1–45% <i>M</i> 7.5%	91% scalds	1–4 wks
Bakker, Van der Heijden et al. (2013)*	Longitudinal	Netherlands and Belgium	186 mothers and 159 fathers (147 couples)	65% boys	0–4 yrs <i>M</i> 1.8 yrs	1–45% <i>M</i> 7.5%	91% scalds	1 mo, 3 mos, 12 mos, 18 mos
Blakeney et al. (1993)	Cross-sectional	United States	89 parents (acute burns), 31 parents (recovering burns)	Nodata	Nodata	Acute burns: 5–98% Recovering burns: 15–98%	Nodata	Acute burns: 1–3 days Recovering burns: 1–5 yrs
Cella et al. (1988)	Cross-sectional	United States	28 mothers and 8 fathers	55% boys	0–15 yrs <i>M</i> <i>n</i> =2 yrs	2–70% <i>M</i> <i>n</i> 14%	Scalds (53%), flame (33%), contact/electrical (14%)	Within 1wk
De Young et al. (2014)	Longitudinal	Australia	111 mothers and 9 fathers	51% boys	1–6.7 yrs <i>M</i> 2.7 yrs	1–27% <i>M</i> 3.16%	Contact (42%), scald (38%), flame (10%), friction (7%), chemical/electrical (3%)	2 wks, 1 mo, 6 mos

ElHamaoui et al. (2006)	Cross-sectional	Morocco	28 mothers	Nodata	4-13 yrs <i>M</i> 8.2 yrs	10-80% <i>M</i> 38.3%	Flame (80%), scald (17%), other (3%)	6 mos-5 yrs <i>M</i> 2.1 yrs
Fukunishi (1998)	Longitudinal	Japan	16 mothers	Nodata	<i>M</i> 8.2 yrs <i>SD</i> 3 yrs	Nodata	Scalds (100%)	1-2 wks, 4 yrs
Hall et al. (2006)	Longitudinal	United States	54 mothers and 8 fathers	69% boys	6-17 yrs <i>M</i> 11.45 yrs	1-85% <i>M</i> 16.9%	Nodata	When child stable, 3 mos
Kent et al. (2000)	Longitudinal	United Kingdom	40 mothers	55% boys	0-4 yrs <i>M</i> 19.2 mos	1-25% <i>M</i> 8.5%	99% scalds	3 days, 6 mos
McGarry et al. (2013)	Cross-sectional	Australia	46 mothers and 17 fathers (5 couples)	64% boys	0-16 yrs	<i>M</i> 4.12% <i>SD</i> 4.05%	Scald (48.8%), contact (32.7%), other (18.5%)	Within 1wk
Meyer et al. (1994)	Cross-sectional	United States	38 mothers	61% boys	4.6-20 yrs <i>M</i> 6.6 yrs**	<i>M</i> 44.4%*** <i>SD</i> 27.3%	Nodata	<i>M</i> 3.6 yrs
Odar et al. (2013)	Cross-sectional	United States	37 mothers and 8 fathers	69% boys	0-6 yrs <i>M</i> 21.9 mos	1-9% <i>M</i> 2.67%	Contact (44%), scald (27%), friction (20%), flame (9%)	14-360 days
Phillips & Rumsey (2008)	Cross-sectional	United Kingdom	Inpatients: 16 parents Outpatients: 56 parents	59% boys	0-14 yrs <i>M</i> 2.6 yrs	1-80%	Scald 88% (inpatient) and 72% (outpatient)	Inpatient: 2 days Outpatient: 6 mos-2 yrs
Rivlin & Faragher (2007a, b)	Cross-sectional	United Kingdom	44 mothers	50% boys**	11-16 yrs	1-20+%**	Nodata	3-14 yrs
Rizzone et al. (1994)	Cross-sectional	United States	24 mothers and 1 father	Nodata	7-18 yrs	1-8% <i>M</i> 37.9%	Nodata	1-17 yrs, <i>M</i> 7.3 yrs
Willebrand & Sveen (2016a)*	Cross-sectional	Sweden	Parents of 107 children (66 mothers, 19 fathers, 2 stepparents, 20 unknown)	64% boys	0.3-15.7 yrs <i>M</i> 3.1 yrs	0.1-70% <i>M</i> 9.4	Scalds (65%), flames (14%), contact (8%), electricity (3%), explosion (1%), unknown (9%)	0.1-9.0 yrs <i>M</i> 4.1

Willebrand & Sveen (2016b)*	Cross-sectional	Sweden	Parents of 101 children (69 mothers, 20 fathers, 2 stepparents, 10 unknown)	62% boys	0.3–15.7 yrs M3.1 yrs	Nodata	Scalds (6%), flames (12%), contact (8%), electricity (3%), explosion (1%), unknown (9%)	0.1–9.0 yrs
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Note. *M* = mean, *SD* = standard deviation, *Mn* = median, yrs = years, mos = months

*More than one publication reporting on the same sample

**Stratified sample

Risk of Bias

Individual Studies

Quality assessment ratings using the QATSDD tool (Sirriyeh, Lawton, Gardner, & Armitage, 2012) are shown in Appendix B. The total scores ranged from 11 to 30 out of 42. The following observations were made about the studies: no studies, with the exception of Cella et al. (1988), provided evidence that the sample size had been considered for the analysis. Eight studies scored low on the criteria: ‘representative sample of target group of a reasonable size.’ This was predominantly the result of small samples sizes and the mother-only samples in many of the studies. Across the studies there was huge a variation in the detail of description given to each stage of the data collection. Some reported only minimal information which raises the issue of replicability. Seven studies also provided no or minimal recruitment data. This information is necessary to assess the representativeness of the sample. In terms of methods of data collection, the majority of studies used self-administered questionnaires which can be open to misinterpretation and lack validity compared to interviews. Willebrand and Sveen’s (2016a, b) were postal questionnaire studies, a method of data collection which is especially prone to producing biased samples (Smeeth & Fletcher, 2002). Finally, in no studies had service-users been involved in the design of the research.

Across Studies

Attempts were made to reduce publication bias by searching the grey literature. However this was not exhaustive and unpublished material may have been available. Another potential bias is language as only studies written in English were included in the review.

Study Outcomes

Table 2 shows the findings of the studies. A range of dependent variables were used

to measure parents' psychological adjustment to their child's burn injury: 12 studies assessed symptoms of Post-Traumatic Stress Syndrome (PTSS) or Post-Traumatic Stress Disorder (PTSD). Nine studies measured depression and seven assessed anxiety. Willebrand and Sveen (2016a, b) also investigated injury-related fear avoidance. This refers to the fear and avoidance of activities that may result in the re-injury of the child (Willebrand & Sveen (2016a).

The 19 publications identified many different risk and protective factors associated with parental adjustment. These will be considered under the following headings: 1) injury factors; 2) child factors; 3) parental factors; and 4) systemic factors.

Table 2

Study Outcomes

Author (Year)	Measures	Analyses	Outcomes	Association between factors and outcomes (positive relationship [+], negative relationship [-], significant [sig], non-significant [ns])
Bakker et al. (2010)	IES, semi-structured interview, feelings of guilt (yes/no question), number of scarred body zones (drawn by mother)	Multiple regression	PTSS	Feelings of guilt (+), scars (<i>ns</i>), interaction between guilt and scars (sig)
Bakker et al. (2012)*	IES, feelings of guilt and anger (5-point Likert scale), life threat to child (yes/no question)	Chi-square test, t-test, correlation, multilevel regression analysis	PTSS	Parent gender (mothers > fathers), relationship status (<i>ns</i>), feelings of guilt and anger (+), life threat (+), accidents occurring at home (+), TBSA (+)
Bakker, Van der Heijden et al. (2013)*	IES, feelings of guilt and anger (5-point Likert scale), life threat to child (yes/no question)	Chi-square test, t-test, multilevel regression analysis	PTSS	Parent gender (mothers > fathers), feelings of guilt and anger (+), life threat (+), TBSA (+), child gender (girls > boys), child age (older children > younger children)
Blakeney et al. (1993)	PSI	Multiple regression	Depression, stress	TBSA (<i>ns</i>)
Cella et al. (1988)	BDI, BHS, IES, ISEL, FOMS, SSAI	Correlation, analysis of variance	PTSD, depression, anxiety and hopelessness	Visibility of burn (on face or hand) (<i>ns</i>), TBSA (+) with intrusion and depression, social support (-) with hopelessness, depression, anxiety and avoidance
De Young et al. (2014)	Brief COPE (self-blame subscale assessed feelings	Correlations, multiple regression, structural	PTSS	Acute parent distress (+), concurrent child PTSS (+), number of invasive

	of guilt), CBCL, DASS-21, DIPA, PDS	equation modelling		procedures (+), feelings of guilt (+), previous trauma history (+)
El Hamaoui et al. (2006)	GAF, HARS, HDRS, MINI	Chi-square test, t-test	Depression	TBSA (+), burn to an only child (+), more than one child burnt (+), complications of the burn injury (+), low social-economic status (-), age and gender of child (<i>ns</i>), mother's age (<i>ns</i>), educational level of the mother (<i>ns</i>)
Fukunishi (1998)	SCID, HDS (subscale assessed feelings of guilt)	Fisher's exact test, correlations, t-test	PTSD	Feelings of guilt (+), TBSA (<i>ns</i>), facial burn (<i>ns</i>)
Hall et al. (2006)	BSI, CPTSD-RI, CSDC, FSI, PCL-C, SASRQ	Correlations, multiple regression	PTSD	Three independent pathways: 1. Conflict with family -> TBSA -> acute dissociation -> PTSD 2. Acute anxiety -> conflict with child after hospital discharge -> PTSD 3. TBSA -> child's acute dissociation -> child's PTSD -> PTSD
Kent et al. (2000)	CBCL, HADS	Repeated measures analysis of variance	Depression, anxiety	Visible burn v. non-visible burn when clothed (<i>ns</i>), TBSA (<i>ns</i>)
McGarry et al. (2013)	CD-RISC, DASS-21, IES-R, STEPP	Correlations, analysis of variance	PTSD, depression, anxiety and stress	History of mental illness (+), experience of past trauma (+), felt helpless at the event (+), witnessed the accident (+), resilience (-), child gender (girls > boys), TBSA (<i>ns</i>), burn location (<i>ns</i>), mechanism of injury (<i>ns</i>), surgical intervention (<i>ns</i>), parent gender (<i>ns</i>), ethnicity (<i>ns</i>), employment (<i>ns</i>), income (<i>ns</i>)
Meyer et al. (1994)	CBCL, PSI, 8SQ	No data	Depression, anxiety, stress	> Depression for parents of children with T-score > 60 on CBCL, TBSA (<i>ns</i>)

Odar et al. (2013)	CSDC, PCL-S, Psychosocial adjustment to burn questionnaire (unpublished)	Correlation, analysis of variance	PTSS	Child age (younger > older children), child PTSS (+), no. family members with mental health diagnoses (+), family stress prior to accident (+), mechanism of injury (sig), no. days in hospital (<i>ns</i>), parent present at accident (<i>ns</i>), parent age (<i>ns</i>), parent gender (<i>ns</i>), parent ethnicity (<i>ns</i>), income (<i>ns</i>), education (<i>ns</i>), marital status (<i>ns</i>), support (<i>ns</i>)
Phillips & Rumsey (2008)	BSHE, CEO, HADS, FAD, MMPI, SDQ	Correlation, multiple regression	Depression and anxiety	<u>Inpatient:</u> Parental extraversion (-) with depression, TBSA (<i>ns</i>), perceived severity of burn (<i>ns</i>) <u>Outpatient:</u> Younger mothers (+) associated with depression and anxiety, emotional stability (-) associated with anxiety. Family functioning (-) associated with depression
Rivlin & Faragher (2007a, b)	GHQ60, EPQ, PSE, SIS, life events questionnaire (unpublished), one question on perceived responsibility (yes/no)	T-test, chi-squared test, analysis of variance	Depression, anxiety, psychiatric diagnosis	Age of child at injury (under 5s > over 5s) for anxiety, location of burn (hands, face > other body areas) for depression, TBSA (<i>ns</i>)
Rizzone et al. (1994)	SCID	Correlation, multiple regression	PTSD	TBSA (+), proximity to accident (<i>ns</i>), perceived stress (<i>ns</i>), social support, interaction between TBSA and proximity (sig)
Willebrand & Sveen (2016a)*	BOQ, IES-R, four questions assessed fear- avoidance beliefs (5-point Likert scale), one question	Chi-square test, t-test, correlation, multiple regression	Injury-related fear- avoidance, PTSD	Injury-related fear-avoidance associated with TBSA (+), length of hospital stay (+), PTSD symptoms (IES) (+), gender of child (<i>ns</i>), gender

	on child's general health (5-point Likert scale)			of parent (<i>ns</i>), education (<i>ns</i>), marital status (<i>ns</i>)
Willebrand & Sveen (2016b)*	BOQ, HADS, IES-R, SDQ, four questions assessed fear-avoidance beliefs (5-point Likert scale), one question on child's general health (5-point Likert scale), one question on perceived lack of support (yes/no)	Chi-square test, t-test, logistic regression	Injury-related fear-avoidance, PTSD, depression, anxiety	Perceived lack of support (+) associated with anxiety and depression, injury-related fear avoidance

Note. Beck Depression Inventory (BDI); Beck Hopelessness Scale (BHS); Burn Outcomes Questionnaire (BOQ); Brief COPE; Brief Symptom Inventory (BSI); Burn Specific Health Scale (BSHS); Child Behaviour Checklist (CBCL); Child Post-Traumatic Stress Disorder Reaction Index (CPTSD-RI); Child Stress Disorders Checklist (CSDC); Civilian version of the PTSD Checklist (PCL-C); Connor Davidson Resilience Scale (CD-RISC); Depression Anxiety Stress Scale-21 (DASS-21); Diagnostic Infant Pre-school Assessment (DIPA); Eight State Questionnaire (8SQ); The General Health Questionnaire (GHQ60); Global Assessment of Functioning Scale (GAF); Goodman's Strengths and Difficulties Questionnaire (SDQ); The Eysenck Personality Questionnaire (EPQ); Family Strains Index (FSI); Hamilton Rating Scale for Depression (HDRS); Hamilton Anxiety Rating Scale (HARS); Hospital Anxiety and Depression Scale (HADS); Impact of Event Scale (IES); Impact of Event Scale-Revised (IES-R); Interpersonal Support Evaluation List (ISEL); Mini International Neuropsychiatric Interview (MINI); Mini Marker Personality Inventory (MMPI); McMaster Family Assessment Device (FAD); Parenting Stress Index (PSI); Posttraumatic Diagnostic Scale (PDS); Present State Examination (PSE); Profile of Mood States (POMS); PTSD Checklist Stressor-Specific version (PCL-S); Structured Clinical Interview for DSM-III-R (SCID); Social Interview Schedule (SIS); Spielberger State Anxiety Inventory (SSAI); Stanford Acute Stress Reaction Questionnaire (SASRQ); The Screening Tool for Early Predictors of PTSD (STEPP); Toronto Childhood Experience Questionnaire (CEQ)

*More than one publication reporting on the same sample

Injury Factors

Objective Measures

The majority of the studies examined the association between characteristics of the burn injury and parental adjustment. With regards to the size of the burn, typically measured as TBSA, five studies reported that larger burns were predictive of high levels of distress in parents (Bakker et al., 2012; Cella et al., 1988; El Hamaoui et al., 2006; Rizzone et al., 1994; Willebrand & Sveen, 2016a) while no association was found in seven of the studies (Blakeney et al., 1993; Fukunishi, 1998; Kent et al., 2000; McGarry et al., 2013; Meyer et al., 1994; Phillips & Rumsey, 2008; Rivlin & Faragher, 2007a, b). Rather than a direct relationship between TBSA and parent PTSD, Hall et al. (2006) reported an indirect effect through mediators: parent's dissociation in the acute phase and child PTSD. In addition, while Bakker et al. (2010) found that burn severity (assessed by mothers' drawings of their child's scarred body zones) was unrelated to symptoms of PTSD in parents, the interaction between feelings of guilt and burn severity was significant. However, in using drawings, this measure of burn severity could be interpreted as subjective as it is open to response bias. Overall, these findings indicate the size of burn injury is inconsistently associated with adjustment in parents, with more studies showing no direct relationship.

The impact of burn visibility was examined in four studies. This refers to injuries located on a child's face or hands which therefore could be seen when fully clothed. Interestingly, despite finding no association with TBSA, Rivlin and Faragher (2007a) reported that parents of children burnt on the face and hands experienced more depressive symptoms, disturbed sleep and expressed more guilt compared to parents of children burnt on other areas. The remaining studies found no significant relationship between the location of the burn and parental adjustment (Cella et al., 1998; Kent et al., 2000; McGarry et al., 2013).

Other characteristics of the burn injury that were associated with adjustment included complications following the burn injury, which was related to depression (El Hamaoui, 2006), and the accident occurring at home, which was linked to PTSS (Bakker et al., 2012). The following variables were only inconsistently related to parental distress: witnessing the accident (McGarry et al., 2013), number of invasive procedures (De Young et al., 2014), length of hospitalisation (Willebrand & Sveen, 2016a) and mechanism of injury (Odar et al., 2013). Thus other objective injury factors are also unreliably associated with parents' psychological adjustment.

Subjective Appraisals

Many of the studies considered the influence of parents' subjective experience of the burn accident: McGarry et al. (2013) reported that feeling helpless at the time of the event was significantly related to PTSS, while parents' perceived life threat to the child predicted PTSS in Bakker et al's (2012) study. In addition, high distress during the acute phase was a risk factor for long-term psychological problems (De Young et al., 2014; Hall et al., 2006). Four samples (described in five papers) assessed feelings of guilt and, in all studies, significant positive associations with symptoms of PTSD were found (Bakker et al., 2010, 2012, 2013b; De Young et al., 2014; Fukunishi, 1998). Bakker, Van der Heijden et al. (2013) also considered feelings of anger and found this to be a stronger predictor of intrusions (a symptom of PTSD) compared to guilt. Therefore the review showed that subjective factors of the burn injury were consistently linked to measures of parental adjustment. This is in contrast to objective factors which appeared to be much poorer predictors.

Child Factors

Parental adjustment was also investigated in relation to child factors, such as gender.

Two studies found that parents of burnt girls were more distressed than parents of boys (Bakker, Van der Heijden et al., 2013; McGarry et al., 2013). However, this finding was not supported by El Hamaoui (2006), Rivlin and Faragher (2007a) or Willebrand and Sveen (2016a) where no effect of gender was found. While two studies reported that parents with younger children showed more adjustment difficulties (Odar et al., 2013; Rivlin & Faragher, 2007a), parents of older children were most distressed in the Bakker et al (2012) study while El Hamaoui (2006) found no relationship. El Hamaoui (2006) further reported that mothers with an only child or mothers who had more than one child that had sustained a burn injury felt the most depressed. In summary, the demographic factors of the child are not robust predictors of parental adjustment.

Across the three studies that investigated the link, the child's symptoms of PTSD were consistently associated with parent PTSD (De Young et al., 2014; Odar et al., 2013; Hall et al., 2006). Furthermore, De Young et al. (2014) concluded that, along with parent acute distress, concurrent child PTSS was the best predictor for parental PTSS at 1 month post-injury and also predicted parents' PTSS at 6 months. Hall et al. (2006) found that, in addition to TBSA, the child's acute dissociation and concurrent PTSS constituted one of three independent pathways to parental PTSD. These studies suggest that parents *become* more distressed over time when their child is also distressed.

Meyer et al. (1994) considered parent reported child internalising and externalising problems. Parents of children with the highest problem scores (T-score > 60) were found to be significantly more depressed than parents of children with lower scores.

Parental Factors

Several studies investigated the impact of pre-existing problems on how well parents

coped following the injury. For instance, a history of previous trauma (De Young et al., 2014; McGarry et al., 2013), mental health difficulties (McGarry et al., 2013), low resilience (McGarry et al., 2013), and emotional instability (Phillips & Rumsey, 2008) were all associated with poorer outcomes. Lower extraversion was additionally related to depression in Phillips and Rumsey's (2008) study. It was therefore a consistent finding that parents who had pre-existing problems experienced more difficulties in the face of this stressor.

With regards to parental demographic factors, age of parent was not associated with adjustment in two studies (El Hamaoui, 2006; Odar et al., 2013). In contrast, Phillips and Rumsey (2008) reported that younger age of mother was a contributing factor in their models for anxiety and depression. While mothers had more symptoms of PTSS compared to fathers in one sample (Bakker, Van der Heijden et al., 2012, 2013), gender of parent was unrelated to adjustment in three others (McGarry et al., 2013; Odar et al., 2013; Willebrand & Sveen, 2016a). However, only the studies by Bakker and colleagues had a good balance of mothers and fathers in their sample. Parents' relationship status, education level, ethnicity, employment and income were consistently found to show no association with parental adjustment (Bakker et al., 2012; El Hamaoui, 2006; Odar et al., 2013; McGarry et al., 2013; Willebrand & Sveen, 2016a). The only exception was El Hamaoui et al. (2006) who reported that mothers of lower social economic status (SES) were more depressed although this effect may be driven by a large proportion of low SES participants (75%) in their sample. In conclusion, as with the child demographic factors, this category for parents was also poorly associated with psychological adjustment.

Systemic Factors

Systemic issues were investigated in a number of different guises including poor social support (Cella et al., 1988; Rizzone et al., 1994; Willebrand & Sveen, 2016b), conflict

with the family and conflict with the child following hospital discharge (Hall et al., 2006), prior family stress and the number of family members with mental health problems (Odar et al., 2013), and family functioning (Phillips & Rumsey, 2008). Excluding 'lack of support' in one study only (Odar et al., 2013) all the above factors were consistently associated with poorer parental adjustment. For parents in Willebrand and Sveen's (2016) study, lack of social support was related to a range of dependent variables: anxiety, depression and injury related fear-avoidance. Likewise poor social support predicted hopelessness, anxiety, depression and avoidance in the study by Cella et al. (1988). Thus, factors relating to systemic issues appear to be important in helping or hindering parents' adjustment to the injury.

Discussion

This review set out to examine psychological adjustment, in particular the risk and protective factors, in parents whose children had sustained a burn injury. The review was able to identify a large number of relevant factors that predicted symptoms of traumatic stress, anxiety and depression. In summary, the review found that objective characteristics of the injury (e.g. burn size, number of invasive procedures, length of hospitalisation) were unreliable predictors of parental adjustment. However, subjective appraisals of the accident (e.g. perceived life threat, helplessness, acute distress, feelings of guilt) were strongly associated with PTSD symptomatology. Pre-existing factors (previous trauma, mental health difficulties, resilience, emotional instability) also put parents at risk of poor adjustment, while demographic variables (e.g. gender, age, marital status) were generally unrelated. Similarly, demographic variables of the child (e.g. gender, age) were inconsistent predictors. PTSD symptoms in the child were significantly associated with parent PTSD across all studies. Lack of social support and other systemic variables, such as family functioning and conflict,

also predicted poor coping in parents.

Many of the findings of this review fit with the hypotheses made by Kazak et al. (2006) in their model of Paediatric Medical Traumatic Stress (PMTS). Firstly, the review supported the assumption that subjective factors are more important than the objective characteristics of a medical event in predicting adjustment. This appears to be a universal finding across medical conditions, for instance, Balluffi and colleagues (2004) also reported that the subjective appraisals of parents of children in intensive care units (ICU) were stronger predictors of later PTSD than doctors' ratings of illness severity. The finding that the subjective experiences of helplessness and perceived life threat were consistently linked to traumatic symptoms is also unsurprising, given that these factors were previously included in the DSM-IV-TR (American Psychiatric Association, 2000) criteria for PTSD. Namely, the first criterion for a diagnosis of the disorder is that an individual must have been exposed to a stressor, such as witnessing the serious injury of others, and their reaction to this event involved 'fear, helplessness, or horror'. These findings therefore highlight the importance of taking into account families' subjective experience of the burn accident (Kazak, Rourke, & Navsaria, 2009), which may be unrelated to the size, severity and prognosis of the injury.

Kazak and colleagues (2006) make some additional predictions about which families who may experience a medical event, such as a burn injury, as being more traumatic. For example, it is suggested that coping and adjustment is relatively stable over time. Therefore, children and parents who are most distressed during the acute phase immediately following an injury or diagnosis also show poorer psychological functioning in the long-term. This assumption was supported by the findings of this review (e.g. De Young et al., 2014; Hall et al., 2006). In addition, Kazak et al. (2006) have proposed that pre-existing factors may predict families who struggle following an illness or injury. Similarly, in this review, parents

with a history of mental health difficulties, prior trauma, low resilience and emotional instability were consistently found to show poorer adjustment. Thus, this review suggests that the families who may benefit from additional support are those who show more distress during the acute phase and/or have pre-existing difficulties.

Another important finding was that child PTSD uniformly predicted parent PTSD. This resembles the high concordance rate of mother and child PTSD symptomatology reported in the literature, for example, following paediatric cancer (Barakat, Kazak, Gallagher, Meeske, & Stuber, 1997), injuries sustained from road traffic accidents (De Vries et al., 1999), and traumatic events such as hurricanes (Scheeringa & Zeanah, 2008). The direction of this effect has been widely discussed. In research on burn injuries, pathway analysis has shown that parent symptoms predicted the development of subsequent child PTSD (Stoddard et al., 2006) and conversely, that a child's acute dissociation served as a predictor for parent PTSD (Rizzone et al., 1994). This relationship is therefore likely to be complex and bidirectional (De Young et al., 2004). In the model of 'relational PTSD' Scheeringa and Zeanah (2001) have proposed a pattern of re-traumatisation whereby a parent and child's distress is exacerbated and maintained by each other. Alternatively, this association has been explained by parent and child sharing the same traumatic experience (Smith, Perrin, Yule, & Rabe-Hesketh, 2001) or a shared genetic vulnerability (Truce et al., 1993).

A protective factor was social support which buffered against anxiety, depression and hopelessness in many of the studies. This is consistent with research on families caring for children with chronic illnesses, where social support was linked to a range of positive outcomes (Garwick, Patterson, Bennett, & Blum, 1998). Of note, it was 'perceived' social support, rather than the number of people in a family's social network that was most

protective. McCubbin and McCubbin (1993) propose that perceived social support constitutes a key resource for families. In their ‘resilience model of family stress, adjustment and adaptation,’ McCubbin and McCubbin (1993) suggest that social support mediates or moderates the impact of stress on a family. In turn this affects the family’s capacity to engage in specific coping behaviours. The review also found that high levels of family conflict and poor functioning predicted adjustment difficulties in parents. This is unsurprising given that these experiences would constitute additional stressors for the family (Sears, Repetti, Reynolds, Robles & Krull, 2016). Overall, these findings suggest that support may enable parents to cope well following a burn injury. The medical team can therefore help to improve families’ outcomes by ensuring that families feel fully supported.

Strengths and Limitations

Individual Studies

The quality assessment ratings of the studies ranged considerably. Overall the studies which scored highly were those that provided detailed descriptions and explanations for each aspect of the research. This transparency is vital in order for researchers to appraise the methodology of the study. Many of the studies showed a good research design. In particular, six studies were longitudinal. For the study of adjustment, this type of design is especially informative as the influence of different factors can be examined over time. A further strength was that many studies employed a consecutive sampling technique. This helped to reduce sampling bias as all parents attending a burns unit who met inclusion criteria were approached to participate. The exceptions were the studies by Willebrand and Sveen (2016a, b) who recruited their sample by sending questionnaires in the post. It is likely that this method introduced bias, as parents who returned the questionnaires probably differed in important ways from those who did not. For example, these parents may have felt less

distressed or were more highly educated.

Overall, a weakness of the majority of the studies was small sample size. Furthermore, fathers were underrepresented, with many studies focusing exclusively on mothers. While this is typical of research in paediatric settings (Seagull, 2000), the lack of data from fathers' perspectives limits our understanding of parental adjustment more broadly and restricts the generalisability of findings (Kazak et al., 2009). An additional limitation was that the majority of studies used self-administered questionnaires for data collection. It has been argued that questionnaires lack the validity of interviews. For example, a participant's experience may not be adequately captured by a set of closed-ended questions (Ackroyd & Hughes, 1981). However, questionnaires also have many advantages. For instance participants may feel more comfortable disclosing difficult thoughts and feelings in a questionnaire relative to face-to-face interviews. While most studies used an objective measure of burn severity (TBSA), it is worth noting that Bakker et al. (2010) asked mothers to draw their child's scarred body zones. It is possible that this may have resulted in reporting bias, with the more distressed mothers and those with more feelings of guilt drawing larger injuries. A significant interaction between guilt and burn size was observed in this study which may be explained by a reporting bias.

Review Process

The review has a number of shortcomings, such as only including papers that were written in English. In addition, while attempts were made to reduce publication bias, this was not explicitly assessed (e.g. using a funnel plot). The search strategy was also broad, which was predominantly the consequence of including the item "injur*" in the search. This pulled up many irrelevant articles, such as those focusing on injury types other than burns. On reflection, more specific search terms, e.g. "thermal injur*", would have ensured a more

focused search. While ‘adjustment’ was narrowly defined, the assumption that ‘good’ adjustment can be measured in terms of low levels of anxiety, depression and traumatic stress may not be accurate. In fact, these types of reactions are normal and expected following a potentially traumatic event such as a burn injury (Price et al., 2016). Coping well following a burn injury may, instead, be better captured using measures that assess quality of life or resilience, neither of which would have met the eligibility criteria for the present review.

The major strength of this review is the comprehensive search strategy, which included both a keyword and a controlled vocabulary search, as recommended by the Cochrane Collaboration guidelines (Higgins & Green, 2011). This was followed by a range of supplementary searches (reviewing reference lists, e-mailing authors) and various attempts to locate grey literatures (searching conference abstracts, EThoS and ProQuest databases). For these reasons, the authors have confidence that the 19 papers identified represent the available research for this review question. While the search generated a large number of results, the decision as to whether papers were eligible for the review was aided by the specific inclusion and exclusion criteria. To help to ensure reliability, a second reviewer was involved in screening articles at each stage of the process and for the quality assessment. However, this could have been extended by replicating the data extraction stage with a second reviewer. Quality assessing the studies was a final strength. By assessing the methodological rigour of studies, the review can have confidence in the credibility of findings.

Clinical Implications

The finding that subjective factors, rather than objective measures, of the injury predicts parental adjustment highlights the need for clinicians to pay close attention to families’ individual injury experience (Kazak et al., 2009). This is particularly important

during the acute phase when children are first admitted to burns units. Kazak and colleagues (2006) suggest that at this stage the medical team have the opportunity to ‘modify’ the injury experience so to make it less distressing for families. This may reduce the impact of long-term difficulties. Children and their parents could, for example, be provided with psychoeducation to normalise the experiences of trauma reactions (Kazak et al., 2006) and receive early signposting to support. In addition, assessments and screening tools should include items that assess parents’ subjective appraisals, pre-existing risk factors and perceived social support. Screening and intervention should also be offered to all families, including families of children with relatively minor burns where the prognosis is good. As the review emphasises the importance of support, services should evaluate how supported families feel by the medical teams involved in their child’s care. Efforts should be made to expand avenues for supporting families. Examples may include improving access to psychological interventions, support groups, a telephone helpline and interventions via the internet (Andersson, Ljotsson, & Weise, 2011).

Research Implications

The articles in this review were, for the most part, biased towards the mother’s perspective. Future studies should therefore address this underrepresentation of fathers. In addition, this literature would benefit from studies with larger sample sizes and longitudinal designs. This would allow for more sophisticated methods of data analysis which may help to elucidate the nature of different associations rather than simply identifying factors that put parents at risk of poor adjustment. Developing a richer understanding of the subjective experiences of families would also be informative. While qualitative studies were excluded in this review, they may be a more appropriate methodology to understand the subjective experiences of families. The quality assessment further highlighted the lack of service-user

involvement in the included studies. It is imperative that research is meaningful and investigates the issues that are important to the families it focuses on. Therefore, future research should aim to conduct research in partnership with parents.

Conclusions

In conclusion, this review has provided an updated synthesis of the literature examining the risk and protective factors for psychological adjustment in parents following a paediatric burn injury. The following factors were identified that may put some parents at risk of poor adjustment: threatening appraisals of the accident, acute distress, feelings of guilt, previous traumatic experiences, a history of mental health difficulties, child PTSD symptoms, lack of social support and poor family functioning. While the methodological quality of the studies was generally satisfactory, the results are biased towards the perspective of the mother and may not be generalisable to fathers. Burns unit services should attend to the subjective experience of the family, rather than just objective markers of the burn severity, and increase the support available to parents.

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Chapter 2: Empirical Paper

Parental Adjustment Following Paediatric Burn Injury: The Role of Guilt, Shame and Self-Compassion¹

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¹ This paper has been prepared for submission to *Psychology & Health*. The journal specifies a 30 page limit inclusive of tables and references (for author guidelines see Appendix C)

Abstract

Objective: Previous research has shown that the objective characteristics of a burn event are poor predictors of parental adjustment. This study will therefore examine the association between subjective factors, namely guilt, shame, self-compassion, and parental adjustment.

Design: Cross-sectional questionnaire study. 91 parents were recruited on the ward or at outpatient clinics during the acute phase following their child's burn injury.

Main Outcome Measures: Questionnaires which assessed adjustment (symptoms of depression, anxiety and post-traumatic stress syndrome [PTSS]) as well as guilt, shame and self-compassion were completed.

Results: Feelings of guilt and shame were associated with poorer adjustment in parents, while parents rated high in self-compassion reported fewer symptoms of depression and PTSS. Guilt and shame showed a differential relationship with measures of adjustment. In particular, shame was a stronger predictor of anxiety than guilt. Objective characteristics of the burn injury were less important than appraisals of guilt and shame for parental adjustment.

Conclusions: Guilt and shame are risk factors for poor adjustment in parents. These two emotions also represent distinct constructs with shame being the more painful experience. Interventions that increase self-compassion may be helpful for some affected parents.

Keywords: Burn injury, children, parents, guilt, shame, self-compassion

Introduction

Paediatric burn injuries are amongst the most traumatic injuries for both children and their parents (Landolt, Buehlmann, Maag, & Schiestl, 2007). Parents are often more psychologically affected by the event than the children themselves (Fukunishi, 1998). Feelings of guilt and self-blame are common, and parents are at risk of developing psychological difficulties (Kent, King, & Cochrane, 2000). Research has consistently shown that a child's post-burn adjustment is significantly related to how well their parents manage to cope with the burn injury (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014). It is therefore beneficial to both children and parents alike that research identifies factors which put families at risk of poor adjustment, and factors that increase resilience. This would have clinical utility in the better identification of families who may require additional support. A number of factors have previously been highlighted in the literature, which may constitute predictors of parental adjustment. These will be outlined below.

Burn severity

The size or severity of the injury may conceivably be one factor that could predict how parents cope in the aftermath of a burn accident. However, the association between burn size and parental adjustment has only inconsistently been demonstrated (e.g. Rizzone, Stoddard, Murphy, & Kruger, 1994), with many studies finding no such relationship (e.g. Phillips & Rumsey, 2008). A similar pattern of results has been observed for other objective measures of the injury, for example the number of invasive procedures (McGarry et al., 2013) and length of hospitalisation (Odar et al., 2013). This fits with Kazak and colleagues' model of Paediatric Medical Traumatic Stress (Kazak et al., 2006). Here the authors suggest that objective factors are often poor predictors of a traumatic reaction in parents and children. Therefore subjective factors, such as how a parent thinks or feels about the accident, may

well play a more important role for the parental adjustment process.

Guilt and Shame

For some parents, the subjective appraisals of their child's burn injury may include feelings of guilt. Guilt is common among parents, with up to 81% expressing feelings of guilt and self-blame in response to burn incidents (Mason, 1993). Parents report remorse for not being able to protect their child (even when the parents themselves were not present at the accident), and many parents question their self-view of being 'good' mothers or fathers (Mason, 1993). Parents may subsequently experience their child undergo medical procedures that inflict more pain, thus re-triggering feelings of guilt (De Young et al., 2014). Scarring also provides a constant reminder of a burn-event which may maintain guilty feelings.

There is evidence that among parents of children with burn injuries, guilt is associated with higher rates of psychological distress (Fukunishi, 1998) especially in parents where difficulties have lasted for many years (Bakker, Van Loey, Van Son, & Van der Heijden, 2010). Outside of the burns literature, the role of guilt is well established in the aetiology and maintenance of difficulties such as post-traumatic stress disorder (PTSD) and depression (Horowitz, 1986). In fact the experience of excessive guilt has been incorporated into the DSM-5 diagnostic criteria (American Psychiatric Association [APA], 2014) and clinical models of these difficulties (e.g. Lee, Scragg, & Turner, 20013). Following a burn injury, feelings of guilt in parents have been found to vary according to location of the injury (guilt more often associated with burns on a very visible part of the body, particularly the face), age of the child (burns on younger children more commonly leading to feelings of guilt) and child gender (parents of girls expressing the most guilt) (Rivlin & Faragher, 2007). However, while guilt is a known risk factor, it has yet to be comprehensively examined. To date researchers have used only crude measurements, such as simply asking parents if they felt responsible for

the injury (Rivlin & Faragher, 2007) or how guilty they felt on a five point Likert scale (Bakker, Van der Heijden, Van Son, & Van Loey, 2013). These methods might be too 'narrow' to capture the complex emotion of guilt (Bakker et al., 2010, p. 659) and thus this area may be advanced through the use of validated measures.

More recently, researchers have turned their focus to the similar yet distinct construct of shame. While the terms guilt and shame are frequently used interchangeably, both within research and by the layperson, theorists have argued that these two emotions represent different constructs (Tangney, 1996). Lewis (1971) defined shame as negative evaluation directed towards the self. With shame, an individual's whole self-concept is under scrutiny, resulting in self-disgust, self-criticism and feelings of worthlessness. By contrast, the negative evaluation in guilt is directed towards an individual's actions. This is a far less painful experience and may motivate an individual to repair damage done to others (Tangney, 1996). Kim, Thibodeau and Jorgensen (2011) argued that these two emotions show a differential association with psychological functioning. In their meta-analysis shame was found to be a stronger predictor of depressive symptoms than guilt leading the authors to advocate that more recognition should be given to the construct of shame. No research to date has considered the role of shame in parents' reactions to a burn accident. However, given that some parents report a loss of self-image regarding being 'good parents' (Mason, 1993), shame may be implicated in parents' experience of their child's burn injury.

Self-Compassion

There are factors that can be protective of experiencing shame, such as adopting a compassionate self-attitude. Self-compassion is an 'adaptive form of self-to-self relating' (Neff, Kirkpatrick, & Rude, 2007, p. 139) and is a promising new avenue in research examining psychological functioning. In particular, self-compassion refers to the propensity

to: 1) engage in self-kindness in response to negative events or perceived self-inadequacy; 2) see one's own experience not as isolated or separate but as common to the human experience; 3) have a balanced perspective on painful thoughts and emotions (Neff, 2003a). This means that in the face of difficult experiences, rather than self-criticising and self-judging, an individual adopts a warm and understanding attitude towards the self (Neff et al., 2007). Previous research has shown that self-compassion predicts life satisfaction and is negatively associated with self-criticism, depression, anxiety and perfectionism (Neff, 2003b). In an experimental task (a pretend job interview) self-compassion was also found to buffer against anxiety (Neff et al., 2007). Similarly, it would be expected that self-compassion would serve as an adaptive coping strategy for parents of children with burns.

Aims

The present study aimed to investigate the association between a number of risk and protective factors (guilt, shame and self-compassion) and parents' psychological adjustment to their child's burn injury. For the purpose of this study poor adjustment was operationalised as the experience of symptoms of post-traumatic stress syndrome (PTSS), depression and anxiety. PTSS refers to subclinical symptoms of traumatic stress which may be experienced in the immediate aftermath of a traumatic event (Kazak et al., 2004). This contrasts with the psychiatric diagnosis of PTSD where clinical level symptomatology persists for more than a month (APA, 2014). This study will measure PTSS as participants were recruited during the acute phase following the burn injury (within a month in some cases) and the experience of participants will be conceptualised as a normal, rather than pathological, reaction to a stressful event.

It was hypothesised that parents with increased feelings of guilt and shame would show poorer adjustment. Furthermore, it was hypothesised that guilt and shame would

differentially predict adjustment, with shame having a stronger relationship. In addition, parents rated higher in self-compassion were hypothesised to demonstrate better adjustment. Finally, the size of the burn and other characteristics of the injury, were predicted to be unrelated to adjustment.

Methods

Parent Characteristics. A total of 91 parents/caregivers (63 mothers, 24 fathers, two grandparents and one step-mother) were recruited. Age ranged from 19 to 66 years ($M = 33.62$, $SD = 8.78$). The ethnicity was predominantly White British (92%). Forty percent of parents witnessed the accident. The timespan between the accident and participation in the study ranged between one and 57 days ($M = 9.71$, $SD = 10.92$).

Child Characteristics. The 91 participants were parents to 71 children (42 boys and 29 girls). This was due to instances where both parents of the same child had taken part in the study. For 51 children, only one parent completed questionnaires while, for 20, both parents participated. The children's ages ranged from four months to 15 years ($M = 4.18$ years, $SD = 4.48$). Ninety one percent of children were White British. Burn injury data was available for 97% of the children. The missing 3% was due to parents not providing consent for the burn data to be used in the study. The size of the burn (measured as Total Body Surface Area [TBSA]) ranged from 0.5% to 22% ($M = 3.88$, $SD = 3.67$). The majority of the children sustained small injuries with 65% of burns being smaller than 2%. Thirty six percent of children required overnight hospitalisation with the length of stay ranging from one to 12 days ($M = 3.88$, $SD = 3.67$). Eight children required a skin graft. The types of injury consisted of scalds (51%), contact (42%), flame (3%), friction (1%), chemical (1%) and frost burns (1%).

Procedure

Prior to recruitment, parents at the hospital's service-user group were involved in reviewing the procedure and the different measures used in the study. Feedback was also given on the information sheet and consent forms. Ethical approval for the study was then

obtained from the University of Liverpool, NHS Research Ethics Committee and the Research and Development Department at Alder Hey Children's Hospital (see Appendix D to G). A power analysis was also computed using G*Power (see Appendix H). This suggested that a sample size of 62 would provide sufficient power for the analyses.

Recruitment took place at a regional paediatric burns unit (Alder Hey Children's Hospital, Liverpool) between February 2016 and November 2016. The inclusion criteria were parents of children under the age of 16 years who had sustained a burn injury within the previous eight weeks. Parents were not approached for the study within the first 24 hours of the accident. Both parents of a child were able to participate. Families were excluded if the burn injury was non-accidental or where there was known social services involvement in relation to the burn injury. Parents had to be proficient in English to participate.

Two post-graduate level psychology researchers recruited all participants to the study with the majority of data (92%) being collected by the author. Parents were recruited on the ward when their child was medically stable. The researcher consulted with nursing staff who identified families that met the inclusion criteria and were not too distressed to be approached. Parents were given a description of the study and an information sheet (see Appendix I). For those who expressed an interest in participating, the researcher returned 24 hours later to take consent and administer the questionnaires (for consent forms see Appendix J). Participants were also recruited at outpatient dressing clinics following their appointment. The same procedure was adopted as above, with the exception that many parents chose to complete the questionnaires at the clinic immediately after being told about the study.

Data consisted of five self-administered questionnaires, a demographic questionnaire and burn injury data. Participants had the option to complete the questionnaires on the ward/in clinic, online via a web link that was given to the participant, or to complete the

questionnaires at home and return these by post. A stamp addressed envelope was provided. The questionnaires took between 15 and 30 minutes to complete. Where consent was given, specific information relating to the burn injury was provided by the burns unit. The research team did not have access to the child's medical files and parents were informed of this. Parents were also told the exact burn injury data that would be sought. It was explained that parents may still choose to participate in the study even if they do not wish to give this consent. Participants were reimbursed for their time with a £5 multi-retailer gift voucher regardless of whether they completed all measures.

Response Rate. During the 10 month period of recruitment, the burns unit treated 525 children. Although it is unclear how many of these families were approached for the study, the current sample represents 13.5% of all patients treated. In total 16 parents completed the questionnaires on the ward and 65 in outpatient clinics. Six were returned by post, a return rate of 12.5% of all questionnaire packs given out. Four questionnaires were completed online indicating that 50% of those who were given a web-link took part in the study.

Measures

With the exception of the demographic questions, which were presented first, the rest of the questionnaires were randomised to prevent order effects. The following questionnaires were completed (see also Appendix K for all included measures):

Traumatic stress symptoms. The Impact of Events Scale-Revised (IES-R) (Weiss & Marmar, 1997). The IES-R measures symptoms of intrusion, avoidance and hyperarousal in response to a specific traumatic event. The total score from the IES-R was used as the measure for PTSS in the analysis. The IES-R shows good reliability and validity (Sundin & Horowitz, 2002). It has been widely used to examine parental adjustment to paediatric burns

(e.g. Bakker et al., 2010). Cronbach's Alpha for the IES-R in the present study was 0.96.

Depression and anxiety symptoms. Depression, Anxiety and Stress Scale 21 (DASS 21) (Lovibond & Lovibond, 1995). This is the short form of the DASS 42 and has 21 items. Two of the three subscales were used in the analysis (depression and anxiety). The DASS 21 has been shown to be a valid and reliable measure of the dimensions of depression and anxiety in both general and clinical populations (Antony, Bieling, Cox, Enns, & Swinson, 1998). Cronbach's Alpha was 0.96.

Guilt. The Trauma-Related Guilt Inventory (TRGI) (Kubany et al., 1996). The TRGI consists of 32 items and measures feelings of guilt in relation to a specific traumatic event. As the TRGI contained no total score, the 'global guilt' subscale was used in the analysis as this represented the actual emotion of guilt. The TRGI showed high construct validity and reliability with participants who have experienced traumatic events (Kubany et al., 1996). Cronbach's Alpha was 0.90.

Shame. The Trauma-Related Shame Inventory (TRSI) (Øktedalen, Hagtvet, Hoffart, Langkaas, & Smucker, 2014). As with the TRGI, the TRSI assesses for event specific feelings of shame. It has 24 items. From the two subscales of shame on the TRIS ('external shame' and 'internal shame'), the 'internal shame' was chosen for the analysis. This captures an individual's own feelings of shame directed towards the self rather than the perception of other people's shame evaluations (Øktedalen et al., 2014). The TRSI showed good construct validity and reliability in a sample of patients treated for PTSD (Øktedalen et al., 2014). A reliable distinction was demonstrated between feelings of guilt and shame, using the TRGI and TRSI respectively (Øktedalen et al., 2014). Cronbach's Alpha was 0.97

Self-compassion. Self-Compassion Scale–Short Form (SCS–SF) (Raes, Pommier,

Neff, & Van Gucht, 2011). The SCS-SF is a 12 item measure which shows near-perfect correlation with the original 26 item version (Raes et al., 2011). The total score from the SCS-SF was used in the analysis. The measure demonstrated good validity and internal consistency within three separate non-clinical samples (Raes et al., 2011). Cronbach's Alpha was 0.74.

Demographics/burn injury data. The following information was collected from the participants: age of child at injury, gender and ethnicity of child and parent, relationship of parent to child, if the parent witnessed the accident (either 'yes' or 'no'). The following information was provided by the burns unit: date of injury, size of burn, type of burn, skin graft required, hospitalisation required, and length of stay.

Data Analysis

The questionnaire data were input into SPSS data files in full by two independent research assistants. A comparison analysis was run between the data files to check for the accuracy of data input. The data were then analysed using IBM SPSS Statistics (version 24) software. Before running the analysis the data were assessed for missing values, normality of distribution and outliers. The influence of demographics/burn injury data on the adjustment variables was examined using t-tests and correlations. Significant findings were included as covariates in the multiple regressions.

To address the hypotheses, correlations were first conducted to test the association between adjustment and feelings of guilt and shame and self-compassion. To investigate whether guilt and shame are differently related to adjustment, multiple regressions were undertaken for each dependant variable. Guilt was entered into the model before shame, because of the already established link between this emotion and the adjustment variables

(e.g. Bakker et al., 2010). Shame was then entered to assess whether it was able to explain an incremental proportion of the variance to guilt. To further examine the association between self-compassion and adjustment, self-compassion was added to the multiple regression in the final step. The variables were entered in stages to establish whether each independent variable was able to explain variance that was over and above the previously entered variables, such that the hypotheses would be supported. Improvements in model fit were assessed at each step by considering the change in $-2 \log$ -likelihood ($-2 LL$) (Bartholomew, Steele, Galbraith, & Moustaki, 2008). This difference was compared to critical chi-square values between the two models.

The multiple regression analysis used a hierarchical linear model with a random intercept (see syntax in Appendix L). This accounted for dependency in the sample owing to instances where both parents of the same child had completed the questionnaires. The two levels were therefore participant (individual level) and family (family group level)². The multiple regression assumptions of multicollinearity, homoscedasticity and independent errors (Berry, 1993) were also checked and none were violated.

Missing Data

Overall 2.14% of all values were missing, while 37 participants (40.66%) had at least one answer missing. A total scale score was calculated using a mean based on 60% of available items where participants had answered at least 60% of questions (see Appendix M). This method for handling missing data is widely used by validated measures (e.g. the Strengths and Difficulties Questionnaire, Goodman, 1997). This resulted in 83 participants having a scale score for each of the six variables (91.2% had full data using listwise deletion).

² The data were also analysed using single level multiple regressions. The pattern of results was the same as the multilevel regression analysis reported below.

The data were assessed for patterns of missing values and Little's MCAR test was calculated. As the test was non-significant, $\chi^2(28) = 27.85, p = .47$, this suggests the data was missing at random. The Expectation Maximization (EM) technique was therefore used to impute the remaining missing scale scores.

Results

The means, standard deviations and the range for the six study variables can be seen in Table 1. Normality of distribution was assessed for the six variables. With the exception of self-compassion which was normally distributed, the remaining variables were significantly positively skewed. Since non-normality violates the assumption for parametric tests, depression, anxiety, PTSS, guilt and shame were transformed with a natural log transformation. Following the transformation, kurtosis and skewness z-scores for shame continued to differ significantly from the normal distribution (± 1.96). This result was driven by 53.84% of participants having a score of 0 for shame. For this reason a dichotomous variable was computed for shame with a median split. The data were subsequently assessed for univariate outliers, using a cut-off point of 3 SD from the mean, while Mahalanobis distance was calculated to check for multivariate outliers. No outliers were identified in the transformed data.

Table 1

Means, standard deviations and range for the study variables

Variable	<i>M</i>	<i>SD</i>	Range
Depression	4.39	5.46	0 – 21
Anxiety	3.48	4.77	0 – 21
PTSS	23.01	19.07	0 – 76
Guilt	1.92	1.68	0 – 10
Shame	2.73	6.00	0 – 28
Self-compassion	3.27	0.68	1.67 – 5

Preliminary Analyses

Correlations (see Table 2) and t-tests were used to identify whether demographic and burn injury factors accounted for any variance in the dependant variables. Younger age of child was found to be associated with higher levels of depression, $r = -.34, p < .01$, anxiety, $r = -.30, p < .01$, and PTSS, $r = -.37, p < .01$, in parents. However, age of parent was not related to adjustment. In addition, there were no significant differences in the measures of adjustment between parents of girls and boys, or between female and male participants.

With regards to the burn injury data: as expected, no association was found between the size of the burn injury (TBSA) and parents' symptoms of depression, anxiety and PTSS. However, length of hospitalisation was significantly correlated with depression, $r = .22, p < .05$, and PTSS, $r = .27, p < .05$. Furthermore parents who had witnessed the burn event ($M = 3.06, SD = .83$) compared to those who had not ($M = 2.45, SD = 1.32$) reported significantly higher scores for PTSS, $t(88.88) = 2.72, p < .01, d = 0.56$. Parents of children who had required a skin graft ($M = 3.21, SD = .61$) also reported significantly more PTSS symptoms, $t(28.71) = 2.80, p < .01, d = .64$, than parents of children who did not ($M = 2.58, SD = 1.25$). Both effect sizes exceeded Cohen's (1988) criterion for a medium effect. Time since injury was unrelated to adjustment. Age of child, length of hospitalisation, witnessing the burn event, and requiring a skin graft were therefore included as covariates in the multiple regressions analyses.

Pearson's correlations were undertaken with guilt but due to the shame variable violating assumptions of normality, correlations with the non-dichotomous variable of shame used Spearman's (see Table 2). Guilt and shame were both significantly positively correlated with all three dependant variables. Therefore, parents who experienced more feelings of guilt and shame also reported higher levels of depression, anxiety and PTSS. In addition, the

findings showed that higher scores for self-compassion were associated with fewer symptoms of depression, $r = -.31, p < .01$, and PTSS, $r = -.24, p < .05$. However, self-compassion was unrelated to anxiety.

Table 2

Correlation coefficients between the study variables

Variable	<u>Variable</u>											
	1	2	3	4	5	6	7	8	9	10	11	
1. Depression	-											
2. Anxiety	.78**	-										
3. PTSS	.68**	.67**	-									
4. Guilt	.52**	.31**	.59**	-								
5. Shame	.57**	.56**	.60**	.50**	-							
6. Self-Compassion	-.31**	-.19	-.24*	-.08	-.36**	-						
7. Age of child	-.34**	-.30**	-.37**	-.40**	-.21*	.06	-					
8. Age of parent	-.183	.15	.20	-.13	-.05	-.04	.46**	-				
9. TBSA	.08	.09	.19	.03	.05	.10	-.01	.10	-			
10. Length of hospitalization	.22*	.13	.27*	.22*	.14	.06	-.15	.10	.65**	-		
11. Time since injury	-.04	-.20	-.07	.17	-.01	-.04	.18	.17	.00	.20	-	

Note. Correlations with shame are based on Spearman's correlations. The remaining variables are Pearson's correlations

** $p < .01$

* $p < .05$

Guilt and shame will show a differential relationship with shame being a stronger predictor

To examine whether guilt and shame were related to psychological adjustment but with shame possibly accounting for more variance than guilt, multiple regressions were calculated for each dependent variable (see Tables 3, 4 and 5).

Age of child was added to the multiple regression in the first step for all three models, while length of hospitalisation was added to depression and PTSS and requiring a skin graft was included in the model for PTSS. Age of the child was the only factor to significantly contribute to the models in step 1. However in subsequent steps, when guilt and shame were entered, no covariates were significant. This would indicate that the variance explained by the covariates was better accounted for by guilt and shame.

In the multiple regressions for depression and PTSS, the associations for guilt and shame remained significant when both variables were added. This would suggest that each emotion made a significant and unique contribution to the model. Furthermore, in both instances when shame was entered, the reduction in $-2LL$ showed that the addition of shame significantly improved the model's overall fit.

The multiple regression for anxiety indicated that adding guilt to the model did not change the $-2LL$. Thus, guilt did not improve the model over and above what was being explained by the covariate: age of child. In contrast, when shame was entered a significant reduction in $-2LL$ was observed, $\Delta -2LL = 24.29(1)$, $p < .01$. This indicates that shame was able to explain significantly more variance for anxiety than guilt and the covariates. Overall this result suggests that shame is a superior predictor of anxiety than guilt.

Table 3

Hierarchical multiple regression models for depression

	β	<i>SE</i>	CI Low	CI High	-2 <i>LL</i> (<i>df</i>)	Residual
M0					265.34 (2)	.46
Age of child	-.01**	.00	-.01	-.00		
Length of hospitalisation	.06	.04	-.01	.13		
M1a					249.04 (3) $\Delta -2LL = 16.30 (1)**$.38
Age of child	-.00	.00	-.01	.00		
Length of hospitalisation	.03	.03	-.03	.10		
Guilt	.83**	.19	.46	1.20		
M1b					232.74 (4) $\Delta -2LL = 16.30 (1)**$.31
Age of child	-.00	.00	-.01	.00		
Length of hospitalisation	.02	.03	.53	-.04		
Guilt	.54**	.18	.18	.90		
Shame	.85**	.19	.47	1.23		
M1c					249.04 (5) $\Delta -2LL = 16.30 (1)*$.29
Age of child	-.00	.00	-.01	.00		
Length of hospitalisation	.03	.03	-.03	.09		
Guilt	.56**	.17	.21	.90		
Shame	.71**	.19	.33	1.10		
Self-compassion	-.32*	.13	-.57	-.07		

Note. 95% Confidence Interval (CI)

** $p < .01$

* $p < .05$

Parents rated high in self-compassion will demonstrate better adjustment

To investigate the influence of self-compassion in relation to feelings of guilt and shame, this variable was added last to the multiple regression models. In the analysis for depression, self-compassion was found to make a significant contribution over and above guilt, shame and the covariates, $\beta = -.32$, $SE = .13$, $p < .05$, and improved the fit of the model, $\Delta -2LL = 16.30 (1)$, $p < .05$. However, in the multiple regressions for anxiety and PTSS, self-compassion did not account for any additional variance. This suggests that while self-compassion can explain a unique proportion of the variance for depression, for anxiety and PTSS any explanatory value of self-compassion is accounted for by the other variables.

Table 4

Hierarchical multiple regression models for PTSS

	β	<i>SE</i>	CI Low	CI High	-2 <i>LL</i> (<i>df</i>)	Residual
M0					284.61 (4)	.59
Age of child	-.01**	.01	-.01	-.00		
Length of hospitalisation	.06	.05	-.03	.15		
Witnessing the event	-.24	.25	-.84	.17		
Skin graft	-.57	.37	-1.31	.16		
M1a					265.352 (5) Δ -2LL = 19.26 (1)**	.46
Age of child	-.00	.00	-.01	.00		
Length of hospitalisation	.05	.04	-.03	.13		
Witnessing the event	-.23	.22	-.68	.22		
Skin graft	-.19	.33	-.86	.48		
Guilt	1.02**	.21	.60	.144		
M1b					254.72 (6) Δ -2LL = 10.63 (1)*	.40
Age of child	-.00	.00	-.01	.00		
Length of hospitalisation	.03	.04	-.04	.11		
Witnessing the event	-.22	.21	-.64	.20		
Skin graft	-.27	.31	-.89	.36		
Guilt	.75**	.21	.33	1.18		
Shame	.78**	.22	.34	1.21		
M1c					253.82 (7) Δ -2LL = 0.91 (1)	.39
Age of child	-.00	.00	-.00	.00		
Length of hospitalisation	.04	.04	-.63	.20		
Witnessing the event	-.21	.21	-.63	.20		
Skin graft	-.26	.31	-.90	.36		
Guilt	.77**	.21	.35	1.19		
Shame	.69**	.23	.23	1.12		
Self-compassion	-.25	.15	-.54	.04		

Note. 95% Confidence Interval (CI)

** $p < .01$

* $p < .05$

Table 5

Hierarchical multiple regression models for anxiety

		β	<i>SE</i>	CI Low	CI High	-2 <i>LL</i> (<i>df</i>)	Residual
M0						268.54 (1)	.45
	Age of child	-.01**	.00	-.01	-.00		
M1a						265.54 (2)	.44
	Age of child	-.00	.00	-.02	.00	$\Delta -2LL = 3.00$ (1)	
	Guilt	.41*	.20	.03	.80		
M1b						241.26 (3)	.33
	Age of child	-.00	.00	-.01	.00	$\Delta -2LL = 24.29$ (1)**	
	Guilt	.02	.19	-.34	.39		
	Shame	1.05**	.19	.67	1.44		
M1c						243.05 (4)	.33
	Age of child	-.00	.00	-.01	.00	$\Delta -2LL = -1.78$ (1)	
	Guilt	.03	.19	-.34	.40		
	Shame	1.02**	.200	.62	1.4		
	Self-compassion	-.09	.13	-.35	.17		

Note. 95% Confidence Interval (CI)

** $p < .01$

* $p < .05$

Discussion

The present study found that guilt and shame predicted all measures of adjustment (depression, anxiety and PTSS). The findings also indicated that these two related emotions were distinct constructs. For example, shame was a much stronger predictor of anxiety than guilt. Parents rated high in self-compassion reported few symptoms of depression and PTSS, however self-compassion was not associated with anxiety. Although burn size was unrelated to parental adjustment, requiring a skin graft was a risk factor for PTSS in parents. Longer stays in hospital were also associated with higher levels of depression and PTSS, while younger age of child and witnessing the burn event predicted symptoms of parental PTSS.

It is unsurprising that guilt and shame were both shown to predict measures of adjustment. There is increasing evidence that the experience of PTSD is not just characterised by fear, but also with anger, guilt and shame (Hathaway, Boals, & Banks, 2010). In fact this

has been recognised in DSM-5's diagnostic criteria (APA, 2014) and clinical formulations of the disorder (e.g. Lee et al., 2001). Similarly, excessive guilt is a feature of 'major depressive disorder' although the importance of shame is often neglected (Kim et al., 2011). The nature of the relationship between guilt, shame and psychological distress is still unclear (Pugh, Taylor, & Berry, 2015) however there are many ideas as to how these emotions might constitute risk and/or maintenance factors. For instance, feelings of guilt and shame are particularly aversive emotional experiences and may elicit avoidance or thought suppression which interferes with the processing of the trauma (Øktedalen et al., 2014). Shame is also associated with self-criticism and rumination (Orth, Berking, & Burkhardt, 2006), key maintenance processes in depression. Future research is therefore needed to elucidate the nature of these complex relationships. This work would have direct clinical implications in terms of what is the target for therapy: guilt and shame cognitions or the psychological distress (Pugh et al., 2015).

Guilt and shame were found to be differentially related to adjustment. Both emotions made unique contributions to the models of depression and PTSS, but shame was found to be a better predictor for anxiety than guilt. This study therefore adds to the growing body of evidence that these emotions represent distinct constructs and should not be considered interchangeable (Lewis, 1971). Kim and colleagues (2011) reviewed research that guilt and shame are distinguishable across a number of dimensions. The focus of negative evaluation is different (specific behaviour vs self-construct) and the accompanying emotions and action tendencies also differ. Shame is characterised by feelings of worthlessness and self-disgust, which result in the behavioural tendencies to withdraw, escape and avoid. In contrast, guilt is associated with feelings of remorse and regret which motivate reparative action (Tangney, 1996). Shame is described as the more 'painful' emotion and, in some studies, has been a

stronger predictor of depressive symptoms (Kim et al., 2011) and PTSD (Leskela, Dieperink, & Thuras, 2002) than guilt. While this was not replicated in the present study, it is not surprising that shame explained more variance of anxiety, especially because of the phenomenological overlap between the behavioural tendency to ‘escape’ in shame and the ‘flight’ response observed in anxiety.

The findings of the present study are in line with previous research examining the role of guilt in parental adjustment following paediatric burn injury. Mason (1993), for instance, identified that the majority of mothers in her qualitative study expressed feelings of guilt or remorse about the burn event. A number of published findings have also reported a positive association between guilt and PTSD (Bakker et al., 2013; De Young et al., 2014), which in some instance was still evident many years after the accident (Bakker et al., 2010; Fukunishi, 1998). In this study, guilt was found to predict symptoms of depression and anxiety as well as PTSS. This research builds on the paediatric burn literature by using a validated measure of guilt, rather than yes/no questions or a Likert scale. Furthermore, the current study is the first to investigate feelings of shame in this population. Shame reactions have been implicated in prior research. For example, participants have reported a loss of self-image of being ‘good’ mothers following the burn event (Mason, 1993). This fits with the definition of shame whereby an individual’s self-concept is the focus of negative evaluation, as opposed to guilt where specific behaviours are under scrutiny (Kim et al., 2011).

The current study is the first to explore the self-attitude ‘self-compassion’ among parents of children who had sustained burn injuries. Self-compassion was negatively correlated with PTSS and explained a significant proportion of the variance in the depression model over and above guilt and shame. This is consistent with previous findings that participants rated high in self-compassion showed better psychological functioning including

less depression (Neff, 2003a). Perhaps unexpectedly, self-compassion was not associated with anxiety which contrasts with prior research (Neff, 2003a; Neff et al., 2007). The discrepancy may be explained by different presentations of anxiety. Parents in the current study were recruited shortly after the burn event so heightened levels of worry and concern would be expected. Therefore the anxiety observed in this study is a normal reaction to stressful circumstances and not necessarily indicative of long-lasting difficulties (Price et al., 2016). In contrast the participants in Neff's studies appeared to show everyday difficulties with anxiety. In addition, self-compassionate parents were found to experience less shame. This would make sense given that shame is characterised by self-condemnation and criticism (Kim et al., 2011) while self-compassion involves adopting a kind and accepting attitude towards the self (Neff, 2003b). Overall these findings would indicate that self-compassion is a protective factor in parents.

In this study, burn size was not associated with parental depression, anxiety or PTSS. This mirrors prior findings that burn injury and severity are often unrelated to adjustment (e.g. McGarry et al., 2013; Phillips & Rumsey, 2008). However, the literature is mixed with some studies reporting the opposite to be true (e.g. Rizzone et al., 1994). Similarly, there have been inconsistent findings with regards to the number of invasive procedures (McGarry et al., 2013) and length of hospital stay (Odar et al., 2013) both of which were significantly related to parental distress in this study. Kazak's model of Paediatric Medical Traumatic Stress (Kazak et al., 2006) suggests that that subjective appraisals of an illness or injury, rather than the objective characteristics (e.g. prognosis and severity), are more powerful predictors of a traumatic response. The model would therefore predict that size of burn, requiring a skin graft and hospitalisation would be less important to adjustment compared to the subjective measures: guilt and shame. This matched the outcomes of the study as the

variance explained by the injury data contributed less to the multiple regression models than guilt and shame.

Strengths and Limitations

The study benefitted from validated measures to capture the complex emotions of guilt and shame rather than the ‘narrow’ measurements of these emotions in previous studies (Bakker et al., 2010, p. 659). Furthermore the measures that were chosen, the TRGI (Kubany et al., 1996) and TRSI (Øktedalen et al., 2014), demonstrated good ecological validity as real feelings of guilt and shame were assessed that were specific to the burn event. This contrasts with the majority of guilt and shame questionnaires which use hypothetical situations to trigger these emotions or focus on guilt and shame ‘proneness’ (Tangney, 1996). Nevertheless a floor effect was observed for the scores on the TRSI (the shame measure). This may suggest that the tool was not sufficiently sensitive or that participants were not comfortable disclosing feelings of shame (Macdonald & Morley, 2001). Otherwise participants simply could not relate to the experience of shame for this event. A further strength, however, was the consecutive sampling technique as researchers attempted to approach all families whose child was being treated at the burn unit. This helped to reduce selection bias as the majority of families who met the study criteria had the opportunity to participate if they wished. In addition, the data analysis used a multilevel model for the multiple regression which was able to account for dependency in the data. This was the result of parents who shared the same child both participating in the study.

One of the major limitations of the study was the over representation of mothers in the sample. While this is typical of paediatric health research (Kazak, Rourke & Navsaria, 2009), it limits our understanding of the father’s perspective and also the generalisability of the findings. With regards to burn size, the sample was relatively homogenous with 65% of

children having sustained a burn injury smaller than 2% TBSA. This is representative of the children being treated by the burns unit but it does not provide the best test for Kazak et al.'s (2006) hypothesis that subjective experience is more important than objective factors for adjustment following a medical event. The design of the study also has a number of limitations: firstly, participants were recruited during the acute phase shortly after the accident. Consequently, these findings provide only a snapshot into the early stages of adjustment and cannot generalise to long-term outcomes. However previous research does indicate that acute distress is predictive of subsequent difficulties (Balluffi et al., 2004). It would also have been informative to have collected data on parents' pre-injury mental health. This is because a history of trauma and mental health problems are known to be strong predictors of poor coping following an injury or illness (Kazak et al., 2006).

Clinical and Research Implications

This study highlights the importance of considering guilt and shame in formulations of psychological distress. These emotions may constitute barriers to treatment (Pugh et al., 2015) and should therefore be addressed directly in therapeutic work. In addition, this study suggests that clinicians and researchers should be mindful that guilt and shame which, although related, are in fact distinct constructs. Kim et al. (2011) have further argued that more recognition should be given to shame (e.g. this emotion is not acknowledged in the DSM-5 criterion for depression) and the outcome of this study would suggest that shame might also be important in the aetiology of anxiety. One implication for supporting parents in paediatric settings would be that screening and assessment tools for psychological distress should include items that address subjective appraisals of the burn event. Furthermore, as injury characteristics were poorly associated with adjustment, interventions should be offered to all families regardless of the size or severity of the burn injury. Where implicated, it might

be helpful to use compassion-based approaches to support parents. Previous trials have shown that brief (3 week) interventions can be effective at increasing self-compassion and reducing psychological distress (e.g. Smeets, Neff, Alberts, & Peters, 2014). This would be especially helpful for parents experiencing high levels of guilt and shame.

While this study was able to demonstrate associations between guilt, shame, self-compassion and psychological adjustment, future research should attempt to determine the nature of these relationships. For instance, it is unclear whether guilt and shame ‘proneness’ represent risk factors that increase a parent’s vulnerability to experiencing difficulties post-injury. Alternatively, feelings of guilt and shame may exacerbate or maintain parents’ distress due to thought suppression and rumination. Guilt and shame may in fact be a product of psychological distress or be entirely unrelated and simply co-occur with poor adjustment. In this study many of the shame questions were not endorsed by parents. It would therefore be helpful that further work is undertaken to validate the TRSI with a non-clinical population. In addition, research focusing on the parental adjustment should attempt to recruit a greater representation of fathers in their samples.

Conclusion

This study has identified that feelings of guilt and shame are risk factors, while self-compassion is a protective factor for psychological adjustment in parents following a paediatric burn injury. Younger age of child, length of hospitalisation, witnessing the event and whether a skin graft was required might also put parents at risk of increased distress. However, overall these objective characteristics were less important than appraisals of guilt and shame for adjustment. The outcomes of the study have informed a number of clinical recommendations for supporting parents, as well as theoretical and research implications for the constructs of guilt and shame.

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Appendices