

# **Early Traumatic Stress Responses in Parents Following a Serious Illness in Their Child: A Systematic Review**

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Abstract A systematic review of the literature investigating the early traumatic stress responses in parents of children diagnosed with a serious illness/injury. A literature review was conducted (September 2013) using Medline, PsycINFO, and CINAHL databases. Twenty-four studies related to parents of children hospitalized due to diagnosis of cancer, type 1 diabetes, meningococcal disease, trauma or serious injury, preterm birth and other serious illnesses requiring admission to intensive care were included. Parents were assessed for early traumatic stress symptoms within 3 months of their child's diagnosis/hospitalization. Prevalence rates of acute stress disorder in parents ranged from 12 to 63 %. Prevalence of posttraumatic stress disorder ranged from 8 to 68 %. Variability was related to methodological factors including differences in study design, timing of assessments, measurement tools, and scoring protocols. Psychosocial factors rather than medical factors predicted parent distress. This review integrates and compares early traumatic reactions in parents with children suffering a range of serious illnesses. Findings suggest a high prevalence of acute and posttraumatic stress symptoms in parents. Methodological inconsistencies made comparison of early traumatic stress

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prevalence rates difficult. Risk factors associated with traumatic stress symptoms were identified.

**Keywords** Psychological assessment · Coping · Children/ adolescents · Families/couples

## Introduction

Serious childhood illnesses or injuries (SCII) that are lifethreatening can have a significant impact on both child and parent psychological wellbeing (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012; Nugent, Ostrowski, Christopher, & Delahanty, 2007). Findings suggest that after a diagnosis of SCII, parents suffer increased psychological distress (Bruce, 2006; Hall et al., 2006; Pai et al., 2007), are at higher risk of developing symptoms of depression and anxiety (Doherty et al., 2009; van Oers et al., 2014), and may be at risk for persisting psychiatric morbidity (Bryant, Creamer, O'Donnell, Silove, & McFarlane, 2012).

A diagnosis of SCII represents a potential psychological trauma for parents, as it involves the risk of death, serious injury, or threat to the child's short and/or long-term health. While most parents adapt well over time to their child's diagnosis (Kazak, 1994; Pai et al., 2007), a subset of parents will develop significant posttraumatic stress symptoms (Bronner et al., 2010; Kazak et al., 2006), including post-traumatic stress disorder (PTSD), which can significantly impair daily functioning (Best, Streisand, Catania, & Kazak, 2001; Young et al., 2003). Although acute traumatic stress reactions can be transient, a proportion of affected individuals will go on to experience debilitating and chronic posttraumatic stress symptoms (PTSS). Early detection of individuals at risk of suffering PTSS

potentially allows for early intervention, and prevention of later mental health problems (Bryant, Sackville, Dang, Moulds, & Guthrie, 1999). Furthermore, given that early parental responses to illness are associated with later psychological adaptation of their children, and that chronic PTSS has been reported in parents of children across an array of illnesses/injuries (Landolt et al., 2012; Stuber & Shemesh, 2006), it is critical to characterize and better understand this response in this population.

Since the inclusion of a diagnosis of a life threatening illness in one's child was recognized as a potentially traumatic event in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV: American Psychiatric Association, 1994), a significant body of literature has utilized a posttraumatic stress framework to examine the psychological responses of parents with ill or injured children (Balluffi et al., 2004; Winston et al., 2002). A smaller body of literature has examined acute or early traumatic stress responses of parents, which may be predictive of longer-term distress. According to the DSM-IV, for both Acute Stress Disorder (ASD) and PTSD, the individual must experience intense fear, horror, or helplessness in response to a traumatic event, as well as symptoms of re-experiencing, avoidance and physiological arousal associated with functional impairment. An ASD diagnosis also requires the presence of dissociative symptoms. ASD designates the presence of symptoms in the early post-trauma period (with onset and duration between 2 days and 4 weeks after the traumatic event), whereas PTSD is diagnosed when symptoms persist for at least 1 month (American Psychiatric Association, 1994). In addition, sub-clinical presentations of PTSD, commonly referred to as PTSS, can result in significant functional impairment for affected individuals (Stein, Walker, Hazen, & Forde, 1997).

Three previous reviews have examined parental posttraumatic stress in the context of childhood illness. Prevalence of parental PTSD following the diagnosis of childhood cancer ranged from 27 to 54 % (Bruce, 2006) and 10-30 % (Taïeb, Moro, Baubet, Revah-Lévy, & Flament, 2003), where PTSD was assessed 3 days to 33 years post-treatment and three to 6 years post-treatment, respectively. In a review of studies examining parents of children diagnosed with a chronic illness who were 3–6 years post treatment, the pooled prevalence of parental PTSD was reported to be 22.8 % (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009). The current review will extend previous work by focussing on parent reactions in the acute period post-diagnosis (within the first 3 months), rather than investigating chronic and longer term parent responses, as has been the case in all the previous reviews. Further, the current review includes 8 studies that were published after the most recent previous review.

To the best of our knowledge, there is no previous systematic review synthesizing the existing evidence for *early* parental traumatic stress following the diagnosis of a range of SCIIs. Such a review will contribute to current understanding of parents' response to the diagnosis of SCII in their child, will inform hospital-wide clinical health service responses to parent distress, and potentially facilitate the development of preventative, evidence-based and generalizable parent interventions which are currently sparse. The majority of studies identified in this review are based on DSM-IV diagnostic criteria, and results remain relevant in the characterization of reactions in parents of children with SCII in a clinical context. Given the recent release of DSM-V (American Psychiatric Association, 2013), which involves some key changes to criteria for PTSD and ASD, a review of the literature to date is particularly timely and will potentially be useful in examining future directions of traumafocused research in the pediatric medical context.

The aim of this systematic review was to provide a critique of studies investigating parental ASD, PTSD or PTSS in the acute period following the diagnosis of a SCII. Our primary research objective is to examine the prevalence of acute and/or posttraumatic stress symptoms in parents in the early period following the diagnosis of a SCII, and determine factors that may impact the variable parental responses to SCII.

#### Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (The PRISMA Statement; Moher, Liberati, Tetzlaff, & Altman, 2009). Three databases were searched in September 2013. There was no restriction on years in the search. The search yielded eligible papers published between 1998 and 2013. The search algorithms used for each database were: Medline: MeSH headings: ('Parents' OR 'Caregivers') AND ('Neoplasms+' OR 'Burns+' OR 'Accidents, Traffic' OR 'Intensive Care, Neonatal' OR 'Intensive Care Units, Pediatric' OR 'Asthma+' OR 'Diabetes Mellitus+' OR 'Chronic Disease' OR 'Cerebral Palsy' OR 'Child Development Disorders, Pervasive+' OR 'Arthritis, Rheumatoid+' OR 'Cystic Fibrosis' OR 'Communicable Diseases+' OR 'Brain Injuries+') AND ('Stress Disorders, Traumatic+'); PsycINFO: Thesaurus terms: ('Parents' OR 'Caregivers') AND ('Neoplasms' OR 'Burns' OR 'Organ Transplantation' OR 'Asthma' OR 'Diabetes' OR 'Intensive Care' OR 'Neonatal Intensive Care' OR 'Chronic Illness' OR 'Cerebral Palsy' OR 'Pervasive Developmental Disorders' OR 'Rheumatoid Arthritis' OR 'Cystic Fibrosis' OR 'Infectious Disorders' OR 'Traumatic Brain Injury') AND ('Posttraumatic Stress Disorder' OR 'Acute Stress

Disorder'); CINAHL: Thesaurus terms: ('Parents+' OR 'Caregivers') AND ('Neoplasms+' OR 'Burns+' OR 'Accidents, Traffic' OR Intensive Care Units, Pediatric+' OR 'Chronic Disease' OR 'Asthma+' OR 'Diabetes Mellitus+' OR 'Cerebral Palsy' OR 'Child Development Disorders, Pervasive+' OR 'Arthritis, Rheumatoid+' OR 'Cystic Fibrosis' OR 'Communicable Diseases+' OR 'Brain Injuries+') AND ('Stress Disorders, Post-Traumatic+').

Inclusion criteria were observational or interventional studies, published in English in a peer-reviewed journal, with a quantitative design, that assessed early posttraumatic stress symptoms in parents with a child: (1) 18 years or younger; (2) diagnosed with a SCII which involved threat of death or physical integrity of the child; and (3) diagnosed/hospitalized less than 3 months prior to assessment. A standardized measure of PTSS, ASD or PTSD was also a requirement. The search resulted in 209 abstracts after duplicates were removed, which were screened by the primary authors. Where abstracts were relevant or where review was not possible from the abstract alone, full text articles were retrieved (n = 70). Studies not meeting inclusion criteria were discarded (n = 185; see Fig. 1). Reference lists of the included studies were examined manually, yielding an additional six studies, resulting in a total of 30 included studies. Inter-rater agreement between the two reviewers regarding article eligibility for inclusion was 100 %.

#### **Quality Assessment**

A quality assessment approach previously described (Jackson, Cheater, & Reid, 2008) was undertaken, with each included study independently assessed by the primary authors. This particular quality assessment approach was chosen as it is utilizes validated tools (Jackson et al., 2008), offers a systematic approach to quality assessment, and has been used in previous systematic reviews involving similar samples (Green, Knight, McCarthy, & DeLuca, 2013; Wakefield, McLoone, Butow, Lenthen, & Cohn, 2011). This approach consists of 15 quality criteria (see Table 1). Interrater agreement was 97.7 % and Kappa corrected agreement was 93.6 %. The majority of studies described an explicit theoretical framework, study aims, data collection and analysis procedures, evidence of critical reflection, use of validated measures and study limitations (see Table 1). However, study samples were often poorly described (41.6 %), and a very limited number of articles included a control group (8.3 %). Overall, the quality of included studies was variable. Thirteen studies were considered 'high quality' (i.e., >13 criteria met) and six studies were considered 'poor' quality (i.e.  $\leq 10$  criteria met). In those studies considered to be of poor quality, the quality criteria most frequently not addressed were the inclusion of a control group, a clear description of the sample, a clear description of the data analysis procedure, the use of an appropriate sampling procedure, a description of the validity and reliability of the results, and the provision of information regarding attrition. Poor quality studies were removed from further analysis, leaving a total of 24 included articles.

## Results

### **Characteristics of Study Samples**

Sample size varied from 23 to 460 parents in the studies reviewed; Four studies had a sample less than 50 and nine studies had a sample size that exceeded 200. SCII diagnoses included children: admitted to the NICU or born preterm (n = 4), hospitalized due to road traffic accidents (RTAs; n = 6), with a new cancer diagnosis (n = 5), admitted to the Pediatric Intensive Care Unit (PICU; n = 2), with a new type 1 diabetes diagnosis (n = 1). Four additional studies included multiple medical conditions. Tables 2 and 3 summarize the articles included in the review.

## **Prevalence of Parental Traumatic Stress Symptoms**

Eleven studies examined parental ASD or acute stress symptoms within a period of zero days to less than 4 weeks following diagnosis of a SCII. Nine specifically investigated parental ASD, and two investigated acute PTSS only. Of the nine studies investigating ASD, four also examined parental PTSS in the acute period or PTSD over time. A further 13 studies examined PTSD or PTSS alone across a period ranging from 4 weeks to 3 months. The prevalence of ASD ranged from 12 % in parents of children involved in RTAs to 63 % in mothers of children newly diagnosed with cancer. The majority of studies (n = 7), however, reported a prevalence of approximately 30 %, although two studies of parents of children newly diagnosed with cancer reported ASD rates of 50-60 %. The prevalence of PTSD in parents 30 days to three months post diagnosis ranged from 8 % in fathers of children admitted to the neonatal intensive care unit (NICU) to 68 % in parents of children who were involved in RTA, burn accidents or newly diagnosed with cancer. The majority of studies, however, reported prevalence rates of PTSD between 15 and 25 %.

# **Risk Factors Associated with Parental Traumatic** Stress Symptoms

#### Demographic Factors

With respect to parent gender; four studies did not specify participant gender: two studies recruited only mothers, and







\* Main reasons for exclusions

- Review papers (n=19), news/magazine articles (n=11), book chapters (n=8), dissertations (n=8), case studies (n=4), qualitative methodologies (n=3), commentaries (n=2), studies not in English (n=2).
- 2. Studies that included children older than 18 years (n=21).
- 3. Studies that did not measure parent acute or posttraumatic stress (n=45)
- 4. Studies that measured traumatic stress greater than 3 months post child's initial diagnosis (n=48).
- 5. Studies that did not include a validated measured of acute or posttraumatic stress (n=4).

one study only included fathers. Seven studies reported on approximately equal numbers of mothers and fathers, although in the majority of studies mothers were more highly represented. Overall, demographic factors were not found to consistently predict parent outcomes. Female gender was reported to be associated with the development of acute and posttraumatic parental stress symptoms in many studies investigating gender (n = 6). There were, however, four studies where gender was not associated with acute and/or posttraumatic stress responses. Three studies reported that parents of non-Caucasian ethnicity were at a greater risk for developing early traumatic stress responses, however this finding was not replicated in four other studies. Three studies reported that younger aged parents were more likely to develop acute and/or posttraumatic stress responses than older-aged parents, but three other studies reported no such association. Findings were also inconsistent for socioeconomic status (SES). Four studies reported parents with lower

**Table 1** Percentage of studies scoring "yes" for quality assessmentcriteria (Jackson et al., 2008)

Criteria	Total $n = 24$	%
Explicit theoretical framework identified	24	100
Evidence of critical reflection	24	100
Clear description of data collection	24	100
Clear description of data analysis	24	100
Valid and reliable outcomes	24	100
Sufficient original data	24	100
Clear aims and hypotheses	23	95.8
Appropriate sampling procedure	22	91.6
Findings reported for each outcome	22	91.6
Strengths and limitations stated	22	91.6
Description of validity/reliability of results	21	87.5
Provision of attrition data	20	83.3
Provision of recruitment data	19	79.2
Clear description of sample	10	41.6
Control group	2	8.3

SES were more likely to develop ASD or PTSD, and six other studies described no such relationship. There was some limited evidence that parents with lower levels of education were more likely to develop significant acute and/or posttraumatic stress responses (n = 3). No studies found that child age and gender were associated with parent responses, with seven studies specifically finding no relationship between these factors.

### **Psychosocial Factors**

Parents' previous experience of stressful life events or trauma (n = 8), parent perception of life threat to their child (n = 4), and parent trait anxiety (n = 3) and levels of depressive symptoms (n = 3) were all identified as contributing to the development of acute and posttraumatic symptomatology. Inconsistent findings were reported regarding family structure; one study reported that single parent families were at a greater risk of acute and/or posttraumatic stress symptomatology than two-parent families, and two other studies reported no such association. Likewise, family cohesion (n = 2) and child ASD/ PTSD symptoms (n = 3) were associated with parent psychological ASD and/or PTSD in some studies, but were not found to be related in other studies (n = 2 and n = 2, respectively).

# Medical Factors

Illness severity or length of hospital admission were not associated with parental acute and posttraumatic stress symptomatology in the majority of studies (n = 10). In

contrast, five studies found associations between illness severity, functional status, days in hospital and acute and/or posttraumatic stress responses.

## **Methodological Factors**

Methodological factors identified as important and likely contributing to inconsistencies in findings included: study design, differences in the timing of assessments, variability in measurement tools, and differences in scoring methods. Study designs included cross-sectional, longitudinal, and intervention studies (see Table 2).

#### Assessment Timing

Four of the cross-sectional studies assessed parents within 1 month, and seven assessed parents greater than 1 month (and less than 3 months) after their child's diagnosis. Eight of the longitudinal studies included an assessment time point within 1 month (from 0 days to less than 4 weeks), four had an assessment time point at 1 month, three at 2 months, and three at 3 months post-diagnosis. All longitudinal studies involved assessment time points that were greater than 3 months (beyond the scope of the current review). Three of the longitudinal studies had one assessment time points within the three-month period post-diagnosis. With regard to the intervention studies, one had an assessment time point within 1 month, and one within 2 months post-diagnosis.

#### Measures and Scoring Methods

Six studies used the Acute Stress Disorder Scale (ASDS), and three studies used the Stanford Acute Stress Reaction Questionnaire to measure ASD. For PTSD, the Posttraumatic Diagnostic Scale (PDS) was the most frequently used measure (n = 6), followed by the PTSD Checklist (PCL; n = 4). Other studies used the Perinatal Posttraumatic Stress Disorder Questionnaire, Self-Rating Scale for PTSD, and PTSD Symptom Scale Interview to measure PTSD. Five studies used the Impact of Events Scale (IES). Different scoring methods for measures were also employed, including clinical cutoffs (n = 3), categorical scores (n = 4) and symptom severity scores (n = 9) while others failed to report on the scoring method used and how scores were classified or interpreted (n = 3).

# Discussion

This review systematically examined the current literature exploring the prevalence of acute and/or posttraumatic stress symptoms and/or disorders in parents immediately

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	Reference	Design	Sample	Child illness	Time	Tool	Measurement criteria	Reliability of measure
-	Allenou et al. (2010)	C	72 Mothers, 28 Fathers	Road traffic accidents	5 weeks	PDI, PDQ, PCL-S	Cut-off >44 = probable PTSD	Cronbach's $\alpha = 0.84$
7	Kassam-Adams et al. (2009)	Ц	273 Mothers, 33 Fathers, 28 others	Road traffic accidents	<1 month, <3 months	SASRQ PCL-C	ASD/PTSD: symptom severity score	Not reported-
ŝ	Landolt et al. (2005b)	C	60 Mothers, 53 Fathers	Road traffic accidents & $\geq 24$ h in hospital	4-6 weeks	PDS	Symptom severity	Cronbach's $\alpha = 0.88$ for mothers and 0.89 for fathers
4	Nugent et al. (2007)	Г	85 families	Road traffic accidents	6 weeks	IES-R	Symptom severity, 0-88	Cronbach's $\alpha = 0.95$
Ś	Sturms et al. (2005)	Г	64 parents	Road traffic accidents	3-months post injury	IES	1-7 (mild), 8-25 (mod), 26-75 (serious) score $\geq 26 = high$ PTSD risk	I
9	Winston et al. (2002)	U	64 Mothers, 23 Fathers, 7 other. $n = 94$	Road traffic accidents	Within 1 month	SASRQ	≥3: clinically significant, ≥4: broad distress	Cronbach's $\alpha = 0.80-0.95$
٢	Kazak et al. (2005)	Ι	20 Mothers, 18 Fathers	New cancer diagnosis	0–11 days	ASDS, IES	z-scores to transform ASDS, no dissociation	Cronbach's $\alpha = 0.91-0.95$ for IES
×	McCarthy et al. (2012)	Г	135 Mothers, 85 Fathers	New cancer diagnosis	Within 4 weeks	ASDS	Categorical and continuous score for ASDS	Cronbach's $\alpha = 0.91$
6	Patino-Fernández et al. (2008)	C	129 Mothers, 72 Fathers	New cancer diagnosis	1-2 weeks	ASDS	Categorical (cut off of 56) and continuous score for ASDS	Cronbach's $\alpha = 0.96$
10	Poder et al. (2008)	L	107 Mothers, 107 Fathers	New cancer diagnosis	1 week and 2 months	PCL-C	Score ≥1 re-experiencing ≥3 avoidance, ≥2 arousal = PTSD	Cronbach's $\alpha = 0.86-0.91$ for mothers, and $0.80-0.88$ for fathers
11	Stehl et al. (2009)	I	38 control, 38 treatment	Non malignant tumors	Within 2 months	ASDS	Severity score used to indicate PTSD diagnosis	Cronbach's $\alpha = 0.90$
12	Holditch-Davis et al. (2009)	Ц	177 African American Mothers	Preterm; need ventilation	2 months after term	Ddd	Scores of $\ge 6 =$ elevated PTSD symptoms	Cronbach's $\alpha = 0.83$
13	Lefkowitz et al. (2010)	Г	86 Mothers, 51 Fathers	Neonatal intensive care admission	3–5 days, 30 days later.	ASDS, PCL	ASDS = categorical score PTSD = $\geq 1$ re-experiencing $\geq 3$ avoidance, $\geq 2$ arousal	Not reported-
14	Shaw et al. (2006)	C	25 Mothers, 15 Fathers	Neonatal intensive care admission	2-4 weeks	SASRQ	I	Cronbach's $\alpha = 0.90$
15	Vanderbilt et al. (2009)	C	59 Mothers, 60 control Mothers	Neonatal intensive care admission	After birth	Ddd	Score $\ge 6$ symptoms = probable PTSD	Not reported-
16	Balluffi et al. (2004)	Ц	223 Mothers, 46 Fathers, 4 others	≥48 h in Pediatric intensive care	<28 days, 2 months	ASDS, PCL	N/A	Not reported-
17	Bronner et al. (2008)	C	140 Mothers, 107 Fathers	Ventilated ≥24; Pediatric intensive care ≥7 days	3 months	SRS-PTSD	N/A	Cronbach's $\alpha = 0.87$ for mothers, and 0.84 for fathers
18	Landolt et al. (2002)	C	337 Mothers, 36 Fathers	Type 1 diabetes	6 weeks	PDS	Symptom severity	Cronbach's $\alpha = 0.92$
19	Landolt et al. (2005a)	C	49 Mothers, 48 Fathers	Type 1 diabetes	6 weeks	PDS	Symptom severity	Cronbach's $\alpha = 0.77$ for mothers, and 0.81 for fathers
20	Shears et al. (2005)	Г	60 Mothers, 45 Fathers	Meningococcal disease	Acute, 3 months	IES	Score of $\ge 35 = risk$ of PTSD	1
21	Landolt et al. (2003)	C	180 Mothers, 175 Fathers	Road traffics accidents, cancer, or diabetes	5-6 weeks	PDS	Symptom severity	Cronbach's $\alpha = 0.91$

Table 2 Summary of characteristics and methodologies of studies in the review

Reference	Design	Sample	Child illness	Time	Tool	Measurement criteria	Reliability of measure
22 Landolt et al. (2012)	L	239 Mothers, 221 Fathers	Hospital ≥24 h, cancer, type 1 diabetes	5–6 weeks post diagnosis	PDS	Symptom severity	Cronbach's $\alpha = 0.87$ in mothers and fathers
23 Landolt et al. (1998)	С	23 high risk patients	Road traffics accidents, burn, cancer	6-8 weeks	PSS		I
24 Ribi et al. (2007)	Г	70 Fathers (injuries); 60 Fathers (chronic diseases)	Epilepsy, diabetes, injury cancer hospital ≥24 h	4-6 weeks	SQ	According to DSM-IV and symptom severity	Cronbach's $\alpha = 0.86$
Note							
Disorder/symptoms		Design	Tool				
ASD = acute stress disorder		C = cross-section	nal ASDS =	= acute stress disorder	scale	PDI = peritraumatic distre	ss inventory
PTSD = post traumatic stress d	lisorder	I = intervention	study IES = ii	mpact of event scale		PDQ = peritraumatic diss	ociative experiences questionnaire
PTSS = post traumatic stress sy	ymptoms	L = longitudinal	IES-R =	= impact of event scale	revised	PDS = posttraumatic diag	nostic scale
			PCL =	PTSD checklist (unspe	cified version)	PPQ = perinatal PTSD qu	estionnaire
			PCL-C :	= PTSD checklist (civ	ilian)	PSS = PTSD symptom sc	ale interview
			FCL-S =	= PTSD checklist (spe	cific)	SRS-PTSD = self-rating-s	cale for ptsd
						SASRO = stanford acute	stress reaction guestionnaire

**Fable 2** continued

(<3 months) following the diagnosis of a SCII, the risk factors associated with posttraumatic responses and methodological issues within this body of literature.

## Prevalence

In general, there was a large range (12–63 %) of reported prevalence of ASD, with the majority of studies reporting a prevalence of approximately 24–40 %. Studies involving parents of children newly diagnosed with cancer tended to report higher rates of ASD symptoms. Similarly, there was a large range in the prevalence of PTSD reported (8–68 %), although the majority reported a prevalence of 15–25 %. Overall, the findings indicate that up to one quarter to one third of parents experience traumatic stress symptoms at a clinically significant level following the diagnosis of a SCII in their child.

Some psychosocial factors (prior trauma, history of mental health issues, trait anxiety, and parent perception of life threat to their child) were consistently found to be associated with parental acute and posttraumatic stress symptomatology. Dissociation was also found to be associated with later traumatic stress symptomatology in the one and only study to explore this relationship (Row 1 of Table 3, Allenou et al., 2003). Findings regarding demographic factors were mixed, and child factors such as child age and gender were not found to be associated with parent outcomes. Medical factors (illness severity, length of hospital stay) were either not predictive, or inconsistently predicted, parent outcomes. The finding that medical factors (e.g. illness severity, length of hospital admission) were generally not associated with parental acute and posttraumatic stress symptomatology is consistent with cognitive models of trauma which emphasize the role of dysfunctional, subjective appraisals that individuals make about the trauma (in this case, child illness), rather than the trauma itself as being critical to posttraumatic adjustment (Ehlers & Clark, 2000). It has therefore been suggested that treatment interventions targeting parental psychological variables, regardless of child's medical diagnosis, may have the potential to prevent PTSS (Shaw, Bernard, Deblois, Ikuta, Ginzburg, & Koopman, 2009).

The variable rates of ASD and PTSD reported across the studies reviewed may be related to a range of factors. Firstly, the heterogeneity of the samples described in the field raises the possibility of different pathogenic pathways (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003). For example, the immediate life threat associated with childhood cancer may play an important role for parents, as many of these children are likely to be in the early phases of intense, painful treatments, possibly making the threat of death more salient (Row 21 of Table 2, Landolt et al., 2003; also see Row 22, Landolt et al., 2012). In line with this, other studies reported that mothers who had been in or

Tal	ble 3 Summary of fir	idings of studies in the revie	M				
	Reference	Sample	Child Illness	Tool	Incidence of symptoms	Factors associated with ASD/PTSD/PTSS	Factors not associated with ASD/PTSD/PTSS
-	Allenou et al. (2010)	72 Mothers, 28 Fathers	Road traffic accidents	PDI, PDQ, PCL	Probable PTSD: 18 %	Peritraumatic dissociation being a co-victim or a witness	Age, gender, illness severity, prior trauma
0	Kassam-Adams et al. 2009	273 Mothers, 33 Fathers, 28 others	Road traffic accidents	SASRQ PCL	ASD: 12 %; PTSD: 8 %	Perception of life threat, prior trauma, higher child ASD symptoms, child pain, direct exposure to accident	Gender, ethnicity, income, illness severity
3	Landolt et al. (2005b)	60 Mothers, 53 Fathers	Road traffic accidents & ≥24 h in hospital	PDS	PTSD in 20 % ( $n = 12$ ) Mothers 11.55 (8. 13); 11.3 % ( $n = 6$ ) of Fathers 7.46 (6.73)	Prior trauma	I
4	Nugent et al. (2007)	85 families	Road traffic accidents	IES-R	M (SD): 18.17 (17.27)	Child PTSS levels	I
S	Sturms et al. (2005)	64 parents	Road traffic accidents	IES	16 % $(n = 8)$ had 'serious' PTSS at 3 months	Illness severity, low SES	I
9	Winston et al. (2002)	64 Mothers, 23 Fathers, 7 other. $n = 94$	Road traffic accidents	SASRQ	23 % (n = 22) experienced broad distress	Minority ethnicity, mechanism of injury	Child age/gender, illness severity, parent present at accident, child level of distress
٢	Kazak et al. (2005)	20 Mothers, 18 Fathers	New cancer diagnosis	ASDS, IES	Primary carers M (SD): 34.81 (9.68), 28.31 (11.64) for partners	I	I
×	McCarthy et al. (2012)	135 Mothers, 85 Fathers	New cancer diagnosis	ASDS	63 % Mothers, 60 % of Fathers had ASD. score ≥ 56 in 34 % Mothers M (SD): 0.95 (15.33); 24 %	Female, greater trait anxiety, family functioning, more psychosocial risk factors, lower matemal age, prior trauma	Patient age, gender
					Fathers 45.86 (15.24)		Parent education, ethnicity
							Paternal age Treatment intensity
o	Dotino Eamóndaz	120 Mothers 22 Enthers	Naw concar diamonic	A CD C	3000000000000000000000000000000000000	Uichar troit onviatu	Minority athnicity low CFC
n	et al. (2008)	129 Moutels, 72 Faurels	ivew calleet utagilosis	CUCK	23.2.1 $\%$ ( <i>n</i> = 00) woulds, ( <i>n</i> = 47) Mothers 50.2 (16), 28 $\%$ ( <i>n</i> = 20) Fathers 46.1 (14.8) > 56 cut-off	rigici uau auxery	rationly cumerty, tow 2023, family functioning, relationship status
10	Poder et al. (2008)	107 Mothers, 107 Fathers	New cancer diagnosis	PCL	<ul> <li>33 % ASD, 28 % PTSD. Mothers</li> <li>47.7 (13.2), Fathers 35.5 (9.0)</li> <li>(1 week). Mothers 39. 6 (13.2),</li> <li>Fathers 33.4 (10.2) (2 months)</li> </ul>	Minority ethnicity, parent and child gender, younger age, low education, employment status prior trauma	1
11	Stehl et al. (2009)	38 control, 38 treatment	non malignant tumors	ASDS	49.87 (15.66) for primary, 47.63 (14.08) for secondary caregivers	I	I
12	Holditch-Davis et al. (2009)	177 African American Mothers	Preterm; need ventilation	ЪРQ	M (SD): 4.9 (3.6)	Low education	Parent age, child gender
13	Lefkowitz et al. (2010)	86 Mothers, 51 Fathers	Neonatal intensive care admission	ASDS, PCL	ASD: 35 % of Mothers and 24 % of Fathers; PTSD: 15 % of Mothers and 8 % of Fathers	Greater perception of life- threat, individual/family history of mental health problems	Illness severity, ethnicity

	Reference	Sample	Child Illness	Tool	Incidence of symptoms	Factors associated with ASD/PTSD/PTSS	Factors not associated with ASD/PTSD/PTSS
14	Shaw et al. (2006)	25 Mothers, 15 Fathers	Neonatal intensive care admission	SASRQ	ASD: 28 % ( $n = 11$ )	Female, greater family conflict, altered parenting role, coping style	Illness severity, SES
15	Vanderbilt et al. (2009)	59 Mothers, 60 control Mothers	Neonatal intensive care admission	ЪРQ	ASD: 27 % $(n = 14)$ M (SD): 3.5 (3.3)	Low education, low SES, prior trauma, depression	Child age/gender, illness severity
16	Balluffi et al. (2004)	223 Mothers 46 Fathers, 4 others	≥48 h in Pediatric intensive care	ASDS, PCL	ASD: 32 % ( $n = 87$ )	Perception of life-threat, prior trauma	Child age/gender, parent gender, ethnicity, illness severity previous admissions
17	Bronner et al. (2008)	140 Mothers, 107 Fathers	Ventilated $\geq 24$ ; Pediatric intensive care $\geq 7$ days	SRS-PTSD	PTSD: 15 % ( $n = 21$ ) Mothers and 9.3 % ( $n = 10$ ) Fathers	Female, greater physical sequelae of PICU treatment	Illness severity
18	Landolt et al. (2002)	337 Mothers, 36 Fathers	Type 1 diabetes	SQI	24 % $(n = 9)$ Mothers 11.91 (9.15); 22 % $(n = 8)$ Fathers 9.90 (7.23) = PTSD	I	Parent gender, child age/gender, illness severity, SES, family structure
19	Landolt et al. (2005a)	49 Mothers, 48 Fathers	Type 1 diabetes	SQ4	22.4 % of Mothers M (SD): 11.9 (7.4), 14.6 % Fathers 8.4 (6.2) had PTSD	Female, greater perception of life-threat, length of hospital stay (fathers only)	SES, family structure, child age/gender
20	Shears et al. (2005)	60 Mothers, 45 Fathers	Meningococcal disease	IES	At risk of PTSD: 38 % ( $n = 20$ ) of Mothers and 19 % ( $n = 8$ ) of Fathers	Length of hospital stay, child psychiatric symptoms	I
21	Landolt et al. (2003)	180 Mothers, 175 Fathers	Road traffics accidents, cancer, or diabetes	SQI	16 % of Fathers M (SD): 8.7 (6.9) and 23.9 % of Mothers 11.9 (8.1) had PTSD	Illness severity, high SES, prior trauma, less complete family structure	Child PTSS
22	Landolt et al. (2012)	239 Mothers, 221 Fathers	Hospital ≥24 h, cancer, type 1 diabetes	PDS	29.3 % $(n = 70)$ Mothers M (SD): 12.67 (8.44) and 18.6 % $(n = 41)$ of Fathers 9.11 (7.50) had PTSD	Female, more days in hospital	SES, child age
23	Landolt et al. (1998)	23 high risk patients	Road traffics accidents, burn, cancer	PSS	PTSD: 68 % $(n = 13)$ of parents	I	Illness severity, child age/gender
24	Ribi et al. (2007)	70 Fathers (injuries); 60 Fathers (chronic diseases)	Epilepsy, diabetes, injury cancer hospital ≥24 h	PDS	26 % ( $n = 18$ ) M (SD): 11.04 (7.36) of Fathers (chronic disease), and 12 % ( $n = 8$ ) M (SD): 6.77 (6.09) of Fathers (injuries) had PTSD	Higher neuroticism, acute functional status of child, stress appraisal and coping	Family functioning
Note	0						
Disc	order/symptoms	Desi	gn	Tool			
ASD	= acute stress disorder	. C = C	cross-sectional	ASDS = acute	stress disorder scale	PDI = peritraumatic distress	s inventory
PTS	D = post traumatic stres	ss disorder $I = it$	itervention study	IES = impact of	of event scale	PDQ = peritraumatic dissoc	siative experiences questionnaire
PTS	S = post traumatic stres	s symptoms L = l	ongitudinal	IES-R = impac	st of event scale-revised	PDS = posttraumatic diagno	ostic scale
				PCL = PTSD	checklist (unspecified version)	PPQ = perinatal PTSD ques	stionnaire
				PCL-C = PTS	D checklist (civilian)	PSS = PTSD symptom scal	e interview
				PCL-S = PTSI	O checklist (specific)	SRS-PTSD = self-rating-sca	ale for PTSD
						SASRQ = stanford acute st	ress reaction questionnaire

Table 3 continued

had witnessed an accident that involved their child were significantly more likely to have traumatic stress symptoms (Bryant, Mayou, Wiggs, Ehlers, & Stores, 2004; de Vries et al., 1999). Interestingly, although the threat or salience of death may appear critical in the development of traumatic stress disorders in parents, many studies reported no association between objective medical characteristics (such as length of hospital stay, severity of illness, length of ventilatory support, and risk of mortality) and traumatic stress symptomatology in parents (Row 1 of Table 3, Allenou et al., 2010; Row 16, Balluffi et al., 2004; Row 17, Bronner, Knoester, Bos, Last, & Grootenhuis, 2008; Row 23, Landolt, Boehler, Schwager, Schallberger, & Nuessli, 1998; Row 18, Landolt et al., 2002; Row 13, Lefkowitz, Baxt, & Evans, 2010; Row 14, Shaw et al., 2006). This finding is consistent with Kazak's model of medical traumatic stress which contends that it is the subjective appraisal of threat not illness factors that will predict an individual's response to a diagnosis (Kazak et al., 2006).

Methodological factors also likely contribute to variability in findings. Variations in study design, in particular timing of assessments, likely contributed to variable findings and rendered comparison across studies difficult. For this review, "early" traumatic responses were defined as parental ASD, PTSD or PTSS investigated within 3 months following the diagnosis of a SCII. There is currently limited understanding of the impact of timing of assessment on traumatic stress symptoms. This is especially the case for assessment within the "acute" period, when individuals experience transient stress reactions that will potentially abate in the following days (Bryant, Friedman, Spiegel, Ursano, & Strain, 2011). Determining the optimal time to assess for traumatic stress in the acute period is further complicated by the notion that stress reactions are largely influenced by contextual factors (Bryant et al., 2011). For example, it is possible that the higher rates of ASD symptoms reported in parents of children with cancer may be related to societal associations between cancer and death, or may be associated with the abrupt onset of invasive treatments such as chemotherapy that may be perceived as further threats to the child (Row 8 of Table 2, McCarthy, Ashley, Lee, & Anderson, 2012).

Across all included studies, nine different measures were used. Of these, two different instruments were administered to measure ASD, six to measure PTSD and one to measure symptom severity or risk for PTSD. One study (Row 10 of Table 2, Pöder, Ljungman, & von Essen, 2008) used the PCL-C (which does not measure dissociation) to index ASD. Further, different scoring protocols were employed to describe traumatic stress symptoms. Of the six studies that used the ASDS, three reported both categorical and continuous scores. The other studies did not describe their scoring protocol (Row 16 of Table 2, Balluffi et al., 2004), derived their own (Row 7 of Table 2, Kazak et al., 2005) or used the ASDS to measure PTSD (Row 11 of Table 2, Stehl et al., 2009). Similar ambiguities and variations in scoring protocols were identified in measures of PTSD. Of the six studies that used the PDS, none described their scoring protocol or reported clinical-cutoffs. Of the five studies using the PCL, two studies (Row 13 of Table 2, Lefkowitz et al., 2010; Row 10 of Table 2, Pöder et al., 2008) used a symptom cluster score and three used a symptom severity score (Row 1 of Table 2, Allenou et al., 2010; Row 16 of Table 2, Balluffi et al., 2004; Row 2 of Table 2, Kassam-Adams, Fleisher, & Winston, 2009).

Similarly for the IES, one study reported "high risk" to include individuals who scored above a cut-off of 26 (Row 5 of Table 2, Sturms et al., 2005; IES Dutch translation) and another reported "risk" to include individuals scoring above a cut-off of 35 (Row 20 of Table 2, Shears, Nadel, Gledhill, & Garralda, 2005).

A further issue with respect to measure methodology is the reliance on self-report measures to assess ASD and PTSD. Over 90 % of the studies examined used self-report measures, which do not allow for the assessment of Criterion F for ASD or PTSD in DSM-IV (that the traumatic stress symptoms cause "clinically significant distress or impairment in social, occupational, or other important areas of function"; American Psychiatric Association, 1994, p. 468). Further, evidence suggests that self-report measures often overestimate the rate of ASD and/or PTSD (Jones et al., 2006). Such measurement and methodological issues limit meaningful and useful conclusions regarding prevalence of parental traumatic stress responses. Stuber et al. (2011) noted that some studies focus on the number of stress symptoms present (yes/no for each symptom), while others focus on symptom severity or frequency, and yet others use the formal diagnostic criteria set by the DSM-IV. They argue that the variability in definitions has made it impossible to compare across studies and that, without common criteria defining PTSD, it is unlikely that consistent predictors of PTSD will be identified in clinical studies of childhood survivors of serious illness (Stuber et al., 2011).

Finally, a tendency to under-represent fathers and ethnic minorities in these studies is of concern. Whilst the majority of studies examined represented fathers well, three studies included mothers only (Row 1 of Table 2, Allenou et al., 2010; Row 12, Holditch-Davis et al., 2009; Row 15, Vanderbilt, Bushley, Young, & Frank, 2009) and in seven studies the sample comprised significantly more mothers than fathers. The exclusion of fathers is limiting considering recent evidence supporting the importance of fathers in healthcare contexts (Bronner et al., 2008). At least 10 studies excluded non-English (or relevant local language) speaking families, resulting in a predominately

white, native speaking sample. This is pertinent as there is evidence to suggest that ethnicity, specifically, belonging to a minority ethnic group, may be a risk factor for posttraumatic stress (see Row 10 of Table 3, Pöder et al., 2008).

#### Limitations of this Study

Due to the limited data reported in the studies included in this review, the array of measures administered and scoring methods employed, only qualitative synthesis of findings was possible. In addition, our search was limited to studies published in English, and as such, results may not generalize to non-English speaking countries/cultures. Finally, only a very small number of studies used a control group, although these mostly included intervention studies, comparing the same cohort of families with ill children across different intervention arms. This limitation raises the challenges of incorporating a control group using healthy children in studies investigating posttraumatic stress responses in parents.

# **Future Research**

For future research, consistency and consensus are needed regarding the operational definitions of traumatic stress responses and the measures used, in order to ensure a more standardized approach to data collection and to allow more meaningful comparison between studies. This is a particularly salient issue with the recent release of DSM-V (American Psychiatric Association, 2013) which includes some key changes in this field. In particular, the DSM-V Criterion A requires more explicit information on how the traumatic event was experienced and the subjective reaction of fear and helplessness (Criterion A2) is no longer required. Further, the emphasis on dissociation in an ASD diagnosis is reduced and the addition of a negative mood symptom cluster has been added to ASD and PTSD criteria.

With the release of DSM-V (American Psychiatric Association, 2013) and consistent with recommendations from Stuber et al. (2011), it is postulated that it may be more appropriate to conceptualize the ASD diagnosis as a means to identify individuals with clinically significant trauma reactions, such as marked fear or anxiety, in the initial month post-trauma. That is, acute stress reactions that are severe enough to warrant clinical attention (Bryant et al., 2011), but not prescribing that these symptoms need to be from specific clusters, such as dissociation (Bryant et al., 2011). Requiring a requisite number of symptoms may increase identification of acutely distressed individuals who may benefit from treatment by acknowledging the diversity of acute traumatic stress responses (Bryant et al., 2011). Given the changes to the DSM-V, the synthesis of

findings contained in this review, and which have been based on DSM-IV criteria, are timely. Future research should be directed towards improved consensus on the application of traumatic stress responses to this population, and examination of the sensitivity of the altered DSM-V criteria in identifying distressed parents who would benefit from clinical care.

## **Clinical Implications**

Findings from this review suggest that there is a high prevalence of traumatic stress symptoms in parents with children diagnosed with SCII. These findings contrast with estimates of lifetime prevalence of PTSD in the general adult population, which have been reported to range from 1 to 14 % (American Psychiatric Association, 1994). Importantly, early traumatic stress responses have been identified in parents with children with a range of illnesses and injuries suggesting that hospital-wide approaches for minimizing traumatic stress responses are warranted for children and families in the acute hospital setting. This extends the current literature, with previous reviews only focusing on a single illness group, or on more chronic and long-term outcomes. These findings will help to raise the awareness of medical and psychosocial clinicians about these difficulties and increase understanding of risk factors, which will allow for improved screening and detection of problems within the acute hospital setting. Given the impact that early traumatic responses have on parent and family functioning, and child recovery and outcome, earlier detection of maladaptive psychological responses in parents, combined with targeted intervention, will reduce the risk of chronic mental health problems developing in the longer term.

The development and evaluation of evidence based interventions, which are aimed at ameliorating distress or preventing longer term adjustment issues, and which can be applied within the hospital or community setting in a feasible and effective manner, is an important future goal (Kazak et al., 2005). To date there have been few studies examining the efficacy of psychological interventions of parents of seriously ill children. However, a small number of studies conducted with parents of children with cancer and cardiac disease in the early period following diagnosis have reported promising results for reducing parental distress (Burke et al., 2014; Sahler et al., 2002, 2005) and enhancing child adjustment (Fedele et al., 2013). Given the impact of early traumatic responses on parent and family functioning and child recovery and outcome, the findings of this review indicate that families affected by SCII need psychosocial intervention in the acute phase post the child's diagnosis to reduce the risk of potential long term mental health problems.

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#### **Compliance with Ethical Standards**

**Conflict of interest** Claudia Woolf, Frank Muscara, Vicki Anderson and Maria McCarthy all declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation of (Royal Children's Hospital, HREC 30044) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study. No animal or human studies were carried out by the authors for this article.

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