Trauma and Growth in Parents of Children with Chronic Illness and Brain Injury

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Thesis Portfolio Abstract

Background: Parents of children with chronic physical illness (CPI) may experience poor mental health. There has also been a growing focus on posttraumatic growth (PTG): positive psychological adaptation following the struggle with trauma.

Method: A systematic review was conducted to develop understanding of variables associated with PTG in parents of children with CPI. Quantitative studies across various CPIs were eligible. A cross-sectional study explored the relationship between post-traumatic stress (PTS) and PTG in parents of children with acquired brain injuries (ABI), considering the influential role of coping.

Results: Twenty-nine papers were reviewed. Most had fair methodological rigour and were in oncology samples. Time and social support were positively associated with PTG. Additionally, cognitive factors (illness perception, core belief re-examination, deliberate rumination) may be associated. Anxiety and moderate PTS were also associated with PTG, although several papers failed to find a relationship between PTS and PTG. Interventions may facilitate PTG. In parents of children with ABI (N = 49), PTS and PTG were unrelated. Significant relationships were found between avoidance-coping and PTS, and acceptance-coping and PTG.

Conclusions: PTG experiences in parents of children with CPI and ABI largely align with existing research and models of PTG (Tedeschi & Calhoun, 2004). The PTS and PTG relationship in this population is complex: results from this thesis suggest they may be curvilinearly related, or independent, though sharing common variables. This may result from paediatric CPI characteristics, namely, beyond initial CPI onset, re-traumatisation from medical procedures and acknowledgement of loss. Interventions which encourage social support, approach-oriented coping and reduce avoidance may be beneficial. Empirical study

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results are limited by sample size. Future research should explore the dimensional relationship between PTS, PTG and associated variables. PTG in this population may evolve across time; longitudinal research could strengthen causal inferences and understanding.

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I would also like to express my gratitude to all the organisations that supported recruitment and the parents who took the time to participate in my study and share their experiences. This project wouldn't have been possible without you – thank you so much.

A special thank you to my lovely trainee colleagues and friends. You are a truly wonderful bunch of people and it's been a privilege to share this journey with you.

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Finally, I am thankful to God, my solid rock and peace which has sustained me throughout this journey.

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Chapter One: Introduction to the Thesis Portfolio

Chronic physical illnesses are broadly defined as conditions which require ongoing medical attention, last longer than three months, may be permanent and/or leave residual disability (Centre for Disease Control and Prevention; CDC, 2016; World Health Organisation; WHO, 2021). This may include, but is not limited to, cancer, diabetes, sickle cell disease, and brain injury (WHO, 2021). Prevalence rates of chronic physical illness in school-aged children across developed countries range from 23-27% (Australian Institute of Health; AIH, 2012; Bethell et al., 2011; Brooks et al., 2015). The WHO (2021) recognises the impact these conditions can have on the individual, but also their families and the systems they are embedded in.

Advances in medical knowledge contribute to increasing rates of children living with these conditions (Kish et al., 2018). Treatments are more accessible and easier to administer, sometimes occurring within the family home (Kish et al., 2018). Parents are taking on greater caregiving responsibilities, additional to routine childcare. The wellbeing of parents of children with chronic physical illnesses has been extensively explored (Fotiadou et al., 2007; Cohn et al., 2020; Kazak et al., 2006; Pinquart, 2019). Parents report increased burden, anxiety, depression, denial, anger, low self-esteem, and reduced quality of life (Kazak et al., 2006; Fotiadou et al., 2007; Horton & Wallander, 2001; Kisch et al., 2017). Parent wellbeing is particularly important given its association with the developmental, psychological, and medical needs of the child (Bakula et al., 2019; Brown et al., 2013; Corsi et al., 2014; Law et al., 2019).

A child's diagnosis of a chronic physical illness can be one of the most emotionally challenging experiences for parents. Recent revisions of the DSM include illness of ones' child as a potential trigger to posttraumatic stress (PTS) (Carmassi et al., 2018). PTS is a common response following a stressful or traumatic event, and describes a set of stress-related symptoms including intrusive flashbacks, hyperarousal, and avoidance (Ehlers &

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Clark, 2000). Cognitive models of trauma suggest the incongruency between a trauma and pre-existing schema can manifest as distress (Janoff-Bullman, 1992). From an evolutionary and neurobiological perspective, PTS symptoms characterise a threat response which serves to protect the individual from further threat and/or adversity through fear learning (Liberzon & Ableson, 2016).

Diagnostically, PTS may be considered a disorder (post-traumatic stress disorder; PTSD) when following a traumatic event there is experience of at least one symptom relating to re-experiencing and avoidance, two symptoms associated with negative alterations in cognitions and mood, as well as arousal, with symptoms lasting a duration of at least a month and causing impairment in normal functioning (American Psychiatric Association [APA], 2013). Cognitive models of PTSD emphasise how mental interpretations and appraisals of the event may influence subsequent outcomes as these can influence ongoing feelings of threat and anxiety (Ehlers & Clark, 2000). Moreover, disturbances in autobiographical memory (Ehlers & Clark, 2000) may contribute to the maintenance of symptoms required to meet the one-month duration diagnostic threshold. Due to the diagnostic thresholds required for PTSD, and possible conceptual differences of PTS following medical events (Tedstone & Tarrier, 2003), throughout this thesis PTS will be used to capture a broader and more inclusive range of post-traumatic experiences (including PTSD) in parents of children with CPI.

The literature exploring PTS in parents following the onset of their child's chronic physical illness has been burgeoning (Pinquart, 2019). Kazak and colleagues (2006) posit that PTS in parents of children with chronic physical illnesses is likely to be conceptually different, leading to the development of the 'paediatric medical traumatic stress model'. This model suggests a temporal component of PTS in parents of children with chronic physical illness. Beyond the immediate life threat, complications from treatments, being responsible for procedures that might inflict pain on the child, and hearing about the death of fellow

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patients may be potentially traumatic for parents as their child progresses through treatment (Kazak et al., 2006; Pinquart, 2019). PTS has been documented in parents of children with cancer (Kazak et al., 2000; Yalug et al., 2011), asthma (Kean et al., 2006), diabetes (Landolt et al., 2005), food allergy (Roberts et al., 2021), heart disease (McWhorter et al., 2021), burns (Hall et al., 2006), sickle cell disease (Hofmann et al., 2007), and neurological conditions such as epilepsy (Carmassi et al., 2018) and brain tumours (Westgate, 2019).

Posttraumatic reactions for parents of children with neurological chronic illnesses might be unique (Westgate, 2019). Where there is damage to the brain, the child might exhibit increased neurobehavioral difficulties, physical, cognitive, psychological, and social changes (Savage et al., 2005). Moreover, parents may have to adapt to significant and abrupt personality changes (Jordan & Linden, 2013), leading to experiences of loss and grief (King, 2016). Indeed, familial caregivers of stroke survivors have a high prevalence of PTS (Carek et al., 2010). Although the WHO identifies brain injury as a chronic physical illness, there is a gap in the literature regarding the experience of PTS for parents of children who sustain a brain injury after a period of normal development (i.e., an acquired brain injury; ABI).

Nevertheless, there is an overrepresentation of studies exploring the negative psychological outcomes for parents of children with chronic physical illnesses, and fewer investigating the possibility of positive psychological outcomes (Huppert & So, 2013; Baker et al., 2017). This may be, in part, owing to the dominance of the medical model within healthcare and how psychological practices have historically operated within this framework (Joseph & Linely, 2008). Within clinical psychology, this has narrowed the focus to what is abnormal and deficient, targeting alleviation of symptoms and distress and less explicitly on healthy adjustment (Linley & Joseph, 2004). Whilst alleviation of distress is important, the Department of Health in the United Kingdom (2014) emphasises that mental health is not mere absence of illness – recognising the importance of positive and negative emotional

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states. This is particularly important for conditions which are chronic or enduring, and can lead to permanent change (Graham et al., 2015; Wood et al., 2009).

One positive psychological concept which has received growing interest is posttraumatic growth (PTG). PTG describes the phenomena of positive psychological development following the struggle with trauma, alluding to a higher level of functioning than existed prior to the traumatic event (Tedeschi & Calhoun, 1996; 2004). Different models of PTG have been posited (e.g., Functional Descriptive Model, Tedeschi & Calhoun, 1996; Organismic Valuing Theory, Joseph & Linley, 2005; Biopsychosocial-Evolutionary Theory, Christopher, 2004). Tedeschi and Calhoun's functional descriptive model is the most cited within the literature. This model suggests that trauma challenges our cognitive frameworks of understanding self, world, and others (i.e., schema). Whilst this can cause distress, this can also be fertile ground for redevelopment of schema – assimilating or accommodating the new trauma information, making them more resilient (Tedeschi & Calhoun, 2004). They identify PTG occurring broadly across five domains: relating to others, spirituality, new possibilities, personal strengths, and appreciation for life. Exploration of positive psychological outcomes could better capture the breadth of human phenomenology following a traumatic event (Joseph & Linely, 2005, 2008; Tedeschi & Calhoun, 1996, 2004; Park, 2010).

The occurrence of PTG for individuals with chronic physical health conditions and/or their carers has recently gained traction, given the degree of PTS responses following diagnosis and/or medical intervention (Kritikos et al., 2021; Li et al., 2020). Indeed, some parents experience PTG following their child's diagnosis of cancer (Barakat et al., 2006), diabetes (Hungerbuehler et al., 2011), cystic fibrosis (Byra et al., 2021) and after their child underwent a stem cell transplant (Beckmann et al., 2021). However, like PTS, there is a gap in the literature exploring the possibility of PTG for parents following their child's ABI.

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Similar to PTS, the experience of PTG for parents of children with paediatric illness may be different. Picoraro and colleagues (2014) extend upon the functional descriptive model, proposing that for parents of children with chronic physical illness, PTG might also be influenced by events occurring after the initial trauma. Aligning with the model of paediatric medical stress (Kazak et al., 2006), this acknowledges the temporal element of posttraumatic reactions in these populations, such as rehabilitative surgery which may re-trigger post-traumatic reactions.

PTG is an important concept as it represents a shift in the literature from a disease-focus towards an approach highlighting resilience and growth. Research is conflicting regarding the relationship between positive psychological outcomes and posttraumatic reactions (Zoellner & Maercker, 2006). By its very nature, traumatic events which could lead to PTG are likely to accompany negative affect (Cadell et al., 2014; Hungerbuehler et al., 2011). Simultaneously, PTG may facilitate positive wellbeing, psychological adaptation, quality of life and decrease anxiety, depression and PTS (Helgeson et al., 2006; Yu et al., 2014; Sim et al., 2015; Shakespeare-Finch & Lurie-Beck, 2014). Psychosocial interventions can be effective in reducing distress and facilitating PTG (Li et al., 2020). Yet, given the complexity of relationships reported between PTS, psychosocial outcomes and PTG, a better understanding of the processes associated with PTG in parents of children with chronic physical illness could help tailor interventions to meet the unique needs of this population.

This thesis aimed to extend understanding of PTS and psychosocial factors in relation to PTG in parents of children with chronic physical illnesses. A comprehensive systematic review of the correlates of PTG in parents of children and adolescents with chronic physical illness is presented in Chapter Two. Chapter Four reports a cross-sectional study exploring the relationship between PTS and PTG in parents of children with ABI. Theoretical and contextual links between these chapters are further discussed in Chapter

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Three. Chapter Five and Six present additional methodology and results for the empirical study. Finally, Chapter Seven provides an integration of findings from both studies alongside a discussion of implications and directions for future research. Strengths and limitations of the thesis portfolio overall are presented.

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Chapter Two: Systematic Review

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(Author guidelines in Appendix A)

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What are the Correlates of Posttraumatic Growth in Parents of Children and Adolescents with Chronic Physical Illness?

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Abstract

Caring for a child with a chronic physical illness (CPI) can be distressing. Yet, for some parents, this may encompass posttraumatic growth (PTG). An improved understanding of the variables associated with PTG in this population could promote positive outcomes and inform psychological practice. This systematic review aimed to identify the correlates of PTG in parents of children and adolescents with CPI. Twenty-nine papers including cross-sectional, longitudinal, and randomised controlled trials were included. Most papers were fair quality; all studies were included in synthesis regardless of methodological rigour. Narrative synthesis indicated PTG may increase across time. Social support and elevated anxiety were associated with PTG. The relationship with posttraumatic stress was complex; some studies suggest a curvilinear relationship whilst others failed to find a relationship. There was tentative evidence suggesting engagement with cognitive processes (deliberate rumination, core belief re-examination and illness perception) could increase PTG. Positive relationships were found with religious coping. Finally, PTG may be facilitated through psychosocial interventions which target cognitive reappraisal and rumination. Heterogeneity across independent variables and lack of longitudinal research weakens these conclusions. Overall, correlates of PTG in this population mostly align with recent reviews and theories of PTG.

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Introduction

Chronic physical illnesses (CPIs) are conditions which require ongoing medical attention, last longer than three months, may be permanent and/or leave residual disability (Centre for Disease Control and Prevention; CDC, 2016). Illnesses such as cancer, sickle cell disease and diabetes fall under this definition. Large groups of children undergo painful treatment procedures for these conditions (Kazak et al., 2006).

Parents can hold responsibilities for managing a child's CPI, increasing caregiving demand (Raina et al., 2005). Paediatric CPI has been associated with negative parental psychosocial outcomes (Cohn et al., 2020). Parents report poorer health-related quality of life, increased burden, anxiety, depression, distress, and posttraumatic stress (PTS) (Law et al., 2019; Cohn et al., 2020; Corsi et al., 2021; Kazak et al., 2006). Parents' wellbeing is important, given associations with the child's emotional health, and ability to engage with the child's medical care (Neece, 2014; Corsi et al., 2021).

Whilst caring for a child with CPI may be distressing, it may bring about a sense of purpose and meaning making (Cohn et al., 2020). Parents of children with cancer report increased religiosity (Duran, 2013) and strengthened relationships (Britt, 1992). Posttraumatic growth (PTG), that is, positive psychological change resulting from the struggle with highly challenging circumstances (Tedeschi & Calhoun, 1996), has been increasingly reported in this population (Li et al., 2020).

Theoretical accounts of PTG in parents of children with "serious physical illness" as presented by Picoraro and colleagues (2014), suggest there is limited evidence distinguishing between the domains of PTG (appreciation of life, interpersonal relationships, personal strength, recognition of new possibilities, spirituality). They report scant evidence for the relationship between spirituality and PTG in this population, though fail to report possible explanations.

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Picoraro and colleagues (2014) also note subjective experiences of illness may influence parents' PTG more than objective severity. Self-regulation theory suggests when individuals are faced with the demands of ill health, they develop a set of cognitive representations about their condition which help establish meaning and enable consideration of coping responses (Leventhal et al., 1980; Leventhal et al., 1997). In the development of these cognitive representations, the individual may ascribe positive meaning consistent with PTG (David et al., 2021).

This might encourage self-reflective thinking about one's thoughts, feelings and experiences (i.e., rumination). Rumination can be intrusive (unintentional recollection of an event) or deliberate (intentional reexperiencing of an event) (Brooks et al., 2017). Both have been associated with PTG in parents of children with CPI, with deliberate rumination more strongly correlated (Picoraro et al., 2014). Deliberate rumination may be influenced by social support and optimism, influencing subsequent PTG (Picoraro et al., 2014).

The review by Picoraro et al. (2014) included 55 studies; the sample included parents and the paediatric patient themselves. Other studies were those describing models of PTG in adult populations with traumas from other events to augment synthesis of their model. Responses to trauma are known to vary according to type of traumatic event (Thomas et al., 2021); the applicability of this model to parents of children with CPI is debatable. Furthermore, the methodological rigour of included studies was not reported, reducing validity of conclusions.

Recently, Kritikos et al. (2021) explored benefit finding in paediatric medical populations, synthesising results in line with the personal growth model (Schaefer & Moos, 1992). This model conceptualises growth as a positive coping strategy, which may be influenced by personal characteristics (age, gender), personal resources (optimism), or

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environmental resources (social support). One-hundred-and-ten studies were reviewed across a range of conditions including: acute, chronic, congenital, acquired, functional and neurodevelopmental. Results suggest that optimism (personal resource), social support (environmental resource), positive reappraisal and disruption of core beliefs (identified as coping strategies) were associated with parental PTG. However, conclusions were constrained by methodological limitations: this review utilised a modified version of the Downs and Blacks (1998) quality assessment tool which is not commonly recommended (Ma et al., 2020). The synthesis of this review did not appear to be guided by study quality.

Collectively, the applicability of these reviews (Kritikos et al., 2021; Picoraro et al., 2014) to parents of children with CPI is ambiguous owing to heterogeneity of included studies. This includes studies exploring PTG resulting from traumatic events which are not medical (Picoraro et al., 2014), and diversity of paediatric conditions and lack of subgroup analyses (Kritikos et al., 2021). The types of treatment a child undergoes for CPIs such as cancer – and subsequent impact on a parent – is likely to differ to those for acute, functional, and neurodevelopmental conditions. Trauma type can vary posttraumatic processing and outcomes (Schimmenti, 2018).

Given the outlined limitations of previous reviews, a more methodologically rigorous and focussed review is needed. Moreover, given the involvement of parents in a child's medical care and rehabilitation (Holm et al., 2017), and association between parent and child mental health outcomes (Ljungman et al., 2014), increased conceptualisation of domains of parents' wellbeing, such as PTG, is important. This aligns with a general shift in psychological literature and practice from a deficit-oriented model to a more inclusive and holistic approach, exploring what makes life for all people fulfilling despite suffering (Joseph & Linley, 2008). For parents of children with CPI, an improved understanding of correlates of PTG may improve effectiveness of psychosocial interventions (Roepke et al., 2015), and

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better position services to ameliorate risk factors and facilitate PTG, improving outcomes for parents and subsequently the child (Corsi et al., 2021).

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The aim of this review was to determine what factors are associated with PTG in parents of children and adolescents with CPI.

Research Question:

What are the correlates of PTG among parents of children and adolescents with CPI?

Method

A systematic review and narrative synthesis was conducted using the following guidelines: ‘Systematic Reviews: CRD’s guidance for undertaking reviews in health care’ (Centre for Reviews and Dissemination; CRD, 2009) and ‘Guidance on the conduct of narrative synthesis in systematic reviews’ (Popay et al., 2006). The PICOS (Population, Intervention/Exposure, Comparator Group, Outcomes, Study Design; O’Connor et al., 2008) question and search structure was used. The review question did not include intervention or comparator groups, thus these were not included. Searches were conducted between January and August 2021. The Cochrane database and Prospero were searched to check for similar published reviews, or those in progress. One study registered on Prospero (Kritikos et al., 2021) (reference: CRD42020189339), had similarities to the present study. It was agreed by the reviewers that there were enough differences between the two protocols to proceed with the current review. These included: type of outcomes explored (psychosocial/health outcomes vs any outcome, benefit finding vs posttraumatic growth), population (intellectual disability inclusion vs CPI only), and risk of bias evaluation. A protocol of this review was preregistered with PROSPERO (CRD42021257830).

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Eligibility Criteria

Participants. Papers were eligible where they examined parents and/or primary caregivers of children/adolescents aged 0-18 years. Where the sample of children/adolescents included participants >18 years old, mean age of children/adolescents was required to be <18 years.

CPIs were defined by the National Institute of Health (NIH, n.d.) and Medical Subject Headings (MeSH) and were required to have one of the following: last for 3 months or longer; may get worse over time, be permanent or leave residual disability; caused by non-reversible pathological alteration; require long periods (3+ months) of supervision, observation, or care from healthcare professionals and/or family members. Studies exploring multiple chronic conditions (e.g., comorbid mental health difficulties) were eligible when the primary condition studied was CPI. Studies with a mixed sample of acute and CPI were included where CPI data was reported separately, or where the aggregated data comprised of at least 80% CPI.

Intervention / Independent Variable. Quantitative studies exploring any independent variable measured with a validated psychometric tool in association with PTG were included in this review.

Outcomes. Studies were eligible where PTG was a primary outcome, aligning with the following definition: “Positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events” (Tedeschi & Calhoun, 1996). Studies referring to PTG using different terms (e.g., thriving, adversarial growth etc.) were included where the reviewers agreed it aligned with the above definition and was measured with a validated tool.

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Study Design. Only quantitative studies were eligible, where PTG was a primary outcome. Any quantitative methods were eligible, such as observational (cohort, case-control, cross-sectional, longitudinal), or randomised controlled trials (RCTs). Theses were eligible for this review.

Exclusion Criteria

Studies were excluded when children/adolescents were 18+ years at the time of study; deceased; suffering with chronic mental health conditions; neurodevelopmental conditions (e.g., autism, Down's Syndrome); and medically unexplained symptoms in isolation.

Studies were excluded where validated tools were not used to measure PTG, or independent variables associated with PTG. Review articles, conference abstracts, book chapters, studies not reporting on primary data, qualitative studies, or those not reported in English language were also excluded.

Search Strategy

MEDLINE, Embase, PsychINFO, CINAHL, Web of Science, Published International Literature on Traumatic Stress (PILOTS) were searched from inception to August 2021 (initial searches were conducted in April 2021 and updated in August 2021). The search strategy was as follows: ("Carer*" OR "mother*" OR "mum*" OR "maternal*" OR "father*" OR "dad*" OR "paternal*" OR "guardian*" OR "care giver*" OR "caregiver*" OR "parent*") AND ("child" OR "school age" OR "youth*" OR "juvenile*" OR "child*" OR "pediatric*" OR "paediatric*" OR "teen*" OR "infan*" OR "baby*" OR "toddler" OR "neonate*" OR "adolescen*") AND ("post-traumatic growth" OR "posttraumatic growth" OR "positive growth" OR "benefit finding" OR "stress related growth" OR "stress-related growth" OR "positive change" OR "PTG" OR "positive adaptation" OR "thriving" OR "adversarial growth"). Subject headings were applied where available (see Appendix B for electronic search strategy). Due

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to the diversity of CPIs, manual searches were implemented using the outlined definition. Reference lists of studies meeting the inclusion criteria were searched.

Data Extraction

Data extraction followed CRD guidelines (Akers et al., 2009) and similar reviews (e.g., Kadri et al., 2022). This included: study and participant characteristics, PTG data and associated measure, independent variables in association with PTG and associated measure, summary of findings and relevant statistics. Data extraction was completed by the primary author (AP); 40% of extracted data were checked for reliability by a second reviewer (PW) and uncertainties resolved through a third reviewer (FG).

Quality Assessment

The NIH quality assessment tools (e.g., the quality assessment tool of observational cohort and cross-sectional studies (QATOCCS); NIH, 2014) covers non-randomized observational studies (Ma et al., 2020) which were included in this paper and therefore used in this review. Following the NIH guidance (2014), papers were assigned a qualitative descriptor: poor, fair, good. For RCTs, study quality was assessed using the Cochrane risk-of-bias tool (RoB2) (Sterne et al., 2019; Version 2). RCTs were assigned a qualitative descriptor: high risk, some concerns, low risk. All papers were assigned quality ratings by two independent reviewers (AP and PW); discrepancies were resolved through discussion.

Data Synthesis

Data from eligible papers were subject to narrative synthesis guided by Popay et al., (2006). Given the inclusion of poor-quality studies to reduce bias, synthesis was stratified by study quality resulting from quality assessment (best available evidence) (Higgins et al., 2011; Popay et al., 2006). Those studies which were ranked as good quality were considered best available evidence, those with moderate rankings were considered

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tentative. Meta-analysis was not considered appropriate due to heterogeneity between studies.

Results

Eligible Studies. The initial search produced 2143 results after duplicates were removed. The primary author (AP) screened titles and abstracts for eligibility. Full-text articles of 201 potential papers were retrieved and examined against the inclusion and exclusion criteria. A total of 29 papers, describing 23 studies, were subject to review (Figure 1). Papers reporting on the same studies included: Turner-Sack (2007), Turner-Sack et al. (2015), Kim (2015), Kim (2019), Rosenberg et al. (2019) and Rosenberg et al. (2021). Study details for observational studies can be seen in Tables 1-3; study details for RCTs are presented in Table 4. Details of the quality assessments can be found in Appendix C.

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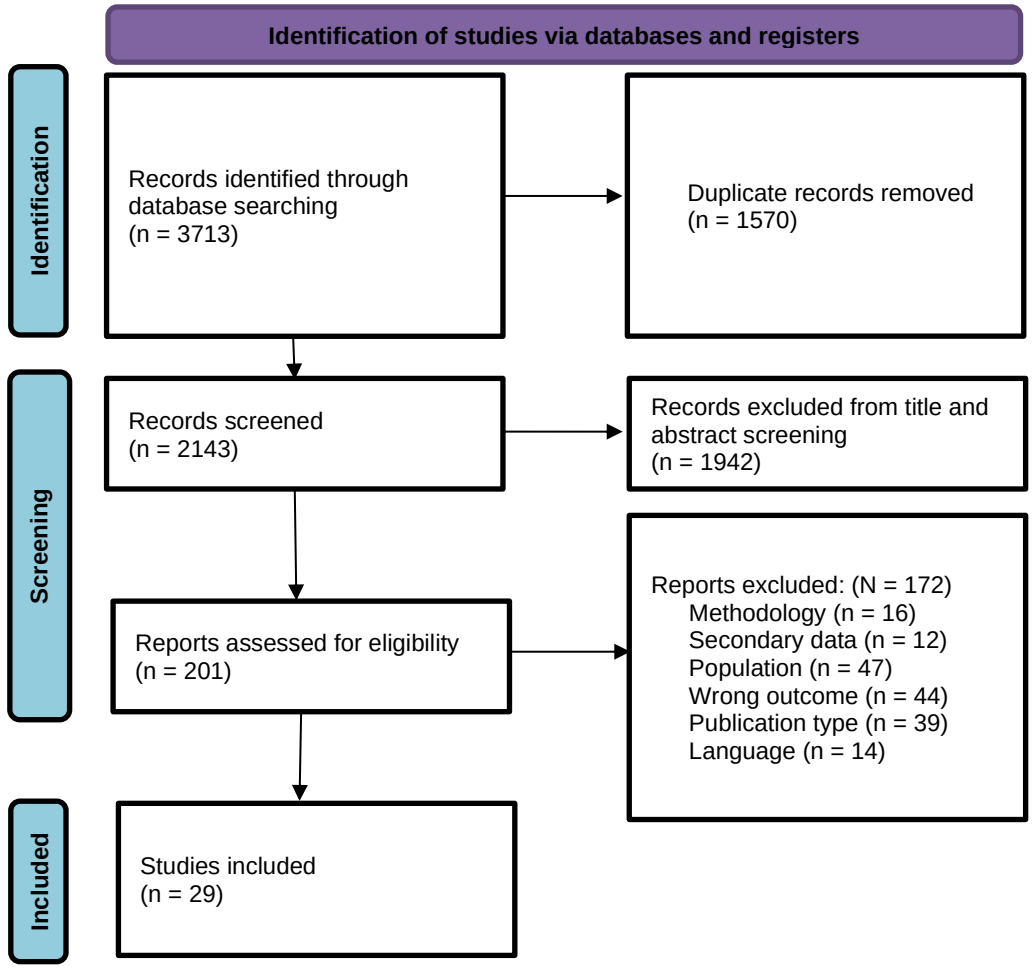
Figure 1

Flow diagram of searches



Note: Adapted PRISMA diagram detailing the flow of studies retrieved from searches through inclusion. *N* = number of articles.

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Table 1

Characteristics of included observational studies (Oncology)

Reference	Sample (N and comparator, where applicable)	Country	Design	Aim	PTG Measure	Independent variable measure(d)	Significant Findings (P<0.05)	Quality
*Barakat, et al. (2020)	Caregivers of children with **cancer** N = 334	USA	Longitudinal, observational	To investigate the predictive value of family psychosocial risk at diagnosis in caregiver resilience (PTG) at the completion of paediatric cancer treatment	PTG-I	Demographics, PTSD (PCL-C), psychosocial risk (PAT version 2), self-efficacy (CHOP-SES), social support (MOS)	**Test:** Correlation/ Regression Overall regression of PTG at Time 2 (T2) included: PTG at Time 1 (T1), PAT at T1, self-efficacy at T1, perceived social support at T1, psychosocial services provided Overall model significant ($F(5, 297) = 23.78$; $R^2 = 0.29$, $p < 0.01$) PTG at T1 predicted greater PTG at T2 ($\beta = 0.53$)	Good
*Behzadi et al. (2018)	Mothers of children with **cancer** N = 180	Iran	Cross-sectional, observation	Determine levels of PTG and its dimensions in mothers of children with cancer	PTG-I	Demographics	**Test:** Correlation Mother's education (r=0.23), male child (r=0.19)	Poor
Bender (2010)	Parents of children with **cancer** N = 62	USA	Cross-sectional, observation	Explore relationships between family members benefit finding (BF)	BFS	Demographics, child's social desirability (child's social desirability questionnaire)	**Test:** Correlation and ANOVA *ANOVA:* Fathers report less BF than mothers (t (58)=5.5) *Correlation:*	Fair

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							Mothers: Child's social desirability (r = 0.27); Acute Lymphocytic Leukaemia diagnosis (r = -0.31) Fathers: Child's race (Caucasian) (r=-0.32)	
Czyzowska et al. (2021)	Mothers of children with **cancer** N = 55	Poland	Cross-sectional, observation	Explore PTG in mothers of children with cancer and relationships between spirituality and PTG	PTG-I (Polish version)	Spirituality (Self-description questionnaire of spirituality)	**Test:** Correlation Total spirituality (r = 0.33) Spirituality subscales*:* ethical sensitivity (r = 0.35), harmony (r=0.35)	Fair
Dirik & Ayas (2018)	Parents of children with **cancer** N = 112	Turkey	Cross-sectional, observation	Explore the predictive power of attributional styles, demographic, and illness factors on PTG	PTG-I (Turkish version)	Demographics, attribution styles (ASQ)	**Test:** Regression, T-Test, ANOVA *T-Test:* Mothers had higher PTG than fathers (*t*(111) = 3.47) *ANOVA:* Parents who worked had higher PTG than those who did not (*F*(2, 109) = 6.3) *Regression:* Overall model included: parents' gender, employment, child's age, illness side effects, composite positive and negative scores of attribution styles, importance for good events and bad events sub dimensions of attribution style	Poor

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							Parents' gender, importance for good events subscale (total score) of attribution style negatively associated with PTG Child's age, importance for bad events subscale (total score), subdimensions of good event attribution (internality, stability, and globality for good events), positively associated (Statistical detail not reported)	
, *Gardner et al. (2017)	Caregivers of childhood **cancer** survivors N = 86	Southeast USA	Cross-sectional observation	Explore predictive ability of demographics, disease and psychosocial factors on parents BF	BFS	Demographics, coping (COPE), spiritual coping (RCOPE), burden (Caregiving burden inventory), illness impact (impact of illness scale), PTS (PCL-C), optimism (LOT-R), social support (social provisions scale)	**Test:** Correlation and Regression *Correlation:* Leukaemia diagnosis (r=0.24), multiple treatment modalities (r=-0.25) Coping: Active (r=0.22), emotional (r=0.29), positive spiritual (r=0.53). Social support (r=0.47), optimism (r=0.36), illness impact (r= -0.3) *Regression:* Overall model included: multiple treatments, relapse, family income, active-, emotion-, and acceptance-coping, positive spiritual coping, social support, optimism, illness impact. Overall model significant ($R^2_{Adjusted}$ = 0.42) Optimism (β = 0.35), positive spiritual coping (β = 0.23), lower	Fair

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							illness impact (β = -0.22) made unique contribution to BF	
*Hong et al. (2019)	Parents of adolescents with **leukaemia** N = 68	Korea	Cross-sectional, observation	Exploration of PTG model	PTG-I (Korean version)	Demographics, core belief disruption (CBI), PTS (IES-R), rumination (ERRI)	**Test:** T-test and Correlation *T-Test:* Mums had higher levels of PTG compared to dads (*t*(67) = 2.09) Religious parents had greater PTG compared to non-religious parents (*t*(67) = 3.58) *Correlation:* Disruption of core beliefs (r=0.77) and deliberate rumination (r=0.32)	Fair
Hullmann (2013)	Parents of children with **cancer** N = 40	USA	Cross-sectional, observational	Explore relationships between cognitive appraisals, PTS and PTG	PTG-I	Demographics, distress (BSI), PTS (IES-R), illness perception (parents' perception of uncertainty scale), illness attitude (child attitude towards illness scale)	**Test:** correlation, regression, ANOVA *Correlation:* Greater illness severity (r=0.24) For those in clinical ranges of PTS, salivary cortisol level (r = 0.49)	Fair
*Hullmann et al. (2014)	Parents of children with **Cancer** N = 85	USA	Cross-sectional, observational	Examine relationships between hope and PTG	PTG-I	Demographics, hope (Hope Scale)	**Test:** Regression Overall model included child age, child gender, parent gender, family income, illness duration and hope. Overall model was significant (*F* (6, 79) = 2.15; R^2 = 0.15) Hope made unique contribution to PTG (β = 0.37)	Fair

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Kim (2015)	Parents of children with **cancer** N = 222	Korea	Cross-sectional, observation	Explore impacts of general and disease-related characteristics on parents' PTG	PTG-I (Korean version)	Demographics	**Test:** T-tests, ANOVAs, Correlation *T-Test* Religious mothers higher PTG compared to non-religious mothers (*t*(221) = -4.5) Mothers PTG higher for second-, or later-born children compared to first born children (*t*(221) = -2.13) *ANOVA:* Mothers who rated their religion as greatly influential experienced more PTG than parents who did not have a religion or felt it had an influence (*F* = 17.15) *Correlation:* Lower distress (r = -0.14)	Fair
*Kim (2017)	Mothers of children with **Cancer** N = 222	Korea	Cross-sectional, descriptive	To test direct and indirect pathways of optimism, core belief disruption, and deliberate rumination on PTG	PTG-I (Korean version)	Optimism (LOT-R), core belief disruption (CBI), social support (MOS), rumination (ERRI)	**Test:** Correlation and SEM *Correlation:* Optimism (r=0.26), core belief disruption (r=0.49), family social support (r=0.27), friend social support (r=0.25), significant other social support (r=0.44), deliberate rumination (r=0.5) *SEM:* *Indirect path:* Optimism to core belief disruption (β =0.3), core belief disruption to deliberate rumination (β =0.55), deliberate rumination to PTG (β = 0.23)	Poor

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							Indirect path: Optimism to core belief disruption (β = 0.3), core belief disruption to social support (β =0.27), social support to PTG (β = 0.31). Core belief disruption to PTG (β =0.24) *Direct path:* Deliberate rumination (β =0.37), Social support (β = 0.31)	
*Michel et al. (2010).	Parents of survivors of **childhood cancer** N = 45	UK	Cross-sectional, observational	Explore contribution of medical variables, and child BF in parents' PTG	PTG-I	Demographics, quality of life, (the SF-12v2), PTS (PCL-C), illness perception (Brief IPQ) Children: Benefit finding scale for children	**Test:** ANOVA, Correlation, Regression *Correlation:* Illness perception: (item 8: 'past illness still affects me emotionally today') (r = 0.41); (Item 7: 'Understanding of past illness') (r = 0.33) *Regression:* Overall model included physical QoL, illness perception (items 7 and 8). Overall model significant (F(3, 33) = 4.26; R^2 = 0.28) Illness perception (item 8: 'past illness still affects me emotionally today') made unique contribution to PTG (β = 0.23)	Fair
*Nakayama et al. (2016)	Parents of children with **cancer** N = 119	Tokyo	Cross-sectional, observation	Exploring variables associated with PTG	PTG-I	Demographics, PTS (IES-R), depression (CESD)	**Test:** T-Test, Regression *T-Test:* Mothers had higher PTG compared to fathers (t(117) = 2.5). Parents had higher PTG if the cancer relapsed compared to no	Fair

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							relapse (t(117) = 5.25); if the child had undergone surgery (t(117) = 2.17), radiation treatment (t(117) = 2.36), stem cell transplant (t(117) = 2.26) compared to those who had not undergone these treatments *Regression:* Overall model included female parent, no recurrence of cancer, no surgery, radiation, or stem cell transplant treatment, no late effects, being off treatment <12 months, being off treatment for >12 months, state anxiety, trait anxiety, low levels of depression, low levels of PTS. Overall model significant (F =3.54; $R^2_{Adjusted}$ = 0.21) Lower trait anxiety (β = -11.94), being a female parent (β = -11.94), child being off treatment for <12months (β = -35.39), surgery (β = 13.79), and late effects (β =35.39) made unique contribution to PTG	
Oginska-Bulik,& Ciechomska (2016)	Parents of children with **cancer** N = 100	Poland	Cross-sectional, observational Between group comparison between mothers and fathers	Explore rumination in association with PTG	PTG-I (Polish version)	Rumination (ERRI)	**Test:** T-Test, Correlation, Regression *T-Test:* Mothers: Recent paediatric cancer diagnosis compared to those whose children were diagnosed earlier (t(98) = -3.58) *Correlation* Mothers: deliberate ruination (r = 0.32).	Poor

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							Fathers: deliberate rumination (r = 0.32) correlated with PTG-I subscale (changes in relationships); intrusive rumination correlated with PTG-I subscale (spiritual changes) (r=0.41) *Regression:* Mothers: Overall model included intrusive and deliberate rumination. Overall model significant (R^2 = 0.1) Deliberate rumination made a unique contribution to PTG (β =0.42) Fathers: Overall model included intrusive and deliberate rumination. Deliberate rumination made unique contribution to certain subscales of PTG: relationships with others (β = 0.36); spiritual changes (β = 0.41). (Remaining statistical detail not reported)	
Turner-Sack, (2007)	Parents of adolescents with **cancer** N = 30	Canada	Cross-sectional, observation	Examine demographics, treatment variables and psychosocial factors in relation to PTG	PTG-I	Demographics, distress (BSI), coping (COPE), life satisfaction (SWLS)	**Test:** Correlation, T-Test, ANOVA	Poor
Turner-Sack et al. (2015)	Parents of adolescents with **cancer** N = 30	Canada	Cross-sectional, observation	Examine demographics, treatment variables and psychosocial	PTG-I	Demographics, distress (BSI), coping (COPE), life satisfaction (SWLS)	**Test:** ANOVA Different levels of PTG across patients, parents, and siblings (F(2, 75) = 5.32). Parents had higher	Poor

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				factors in relation to PTG			levels of PTG compared to healthy siblings (*t*(46) = 2.91)	
Weber (2014)	Parents of children with **Cancer** N = 98	USA	Longitudinal, quasi experimental	Examine demographics, disease variables, and support services on PTG	PTG-I	Demographics, PTS (IES-R)	**Test:** T-Test, Regression/Correlation, Curve estimation analysis *T-Test:* PTG at T2 higher than PTG at T1 (*t*(99) = -8.04) *Curve estimation analysis:* Quadratic regression of PTS on PTG (*F*(2, 108) = 21.14; R^2 = 0.27). Low and high scores of PTS associated with lower PTG. Moderate PTS associated with high PTG *Regression:* Overall model included PTS, time since diagnosis, cancer status, parent gender. Overall model significant (*F*(4, 93) = 5.97; R^2 = 0.17) PTS (β = -0.31), time since diagnosis (β = 0.21) made unique contribution to PTG Overall model predicting PTG at T2 included PTG at T1, utilisation of support groups. Overall model significant (*F*(2, 96) = 110.63; R^2 = 0.69) PTG at T1 (β = 0.82), utilisation of support groups (β = 0.1)	Good

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Note: N = number of participants. *Indicates the study was included in the review by Kritikos et al. (2021). PTG-I = Posttraumatic Growth Inventory; BFS = Benefit Finding Scale; PCL-C = Posttraumatic Stress Disorder Checklist; CHOP-SES = Children's hospital of Philadelphia Self-Efficacy Scale; MOS = Medical Outcomes Study Social Support Survey; LOT-R = Life Orientation Test-Revised; CESD = Centre for Epidemiological Studies Depression Scale; RCOPE = Brief Religious Coping Scale; ASQ = Attribution Style Questionnaire; CBI = Core Beliefs Inventory; IES-R = Impact of Events Scale Revised; BSI = Brief Symptom Inventory; ERRI = Event-Related Rumination Inventory; Brief IPQ = Brief Illness Perception Questionnaire; HADS = Hospital Anxiety and Depression Inventory; SWLS = Satisfaction With Life Scale; SES = Socioeconomic Status.

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Table 2

Characteristics of included observational studies (Mixed samples)

Reference	Sample (N and comparator, where applicable)	Country	Design	Aim	PTG Measure	Independent variable measure(d)	Significant Findings (P<0.05)	Quality
*Cadell et al. (2014)	Parents of children with **life-limiting illness** N = 273	USA and Canada	Cross-sectional, observation	Examine factors associated with growth in parents caring for children with a life-limiting illness	PTG-I	Demographics, caregiver meaning (Meaning in caregiving scale), optimism (LOT-R), religiosity (Spiritual involvement and beliefs scale-revised), depression (CESD), Caregiver burden	**Test:** Structural equation modelling (SEM) *Direct path:* Stress (β = 0.79) *Indirect path:* Personal wellbeing to meaning in caregiving (β = 0.33), meaning in caregiving to PTG (β = 0.81)	Fair
Chardon, et al. (2021)	Parents of children with **hematopoietic stem cell transplant** N = 140	USA	Cross-sectional, observation	Examine associations between positive and negative religious coping on caregiver PTG	PTG-I	Demographics, religious coping (RCOPE), self-efficacy (CHOP-SES), social support (MOS)	**Test:** Correlation and regression *Correlation:* Positive religious coping (r = 0.41), self-efficacy (r = 0.18), social support (r = 0.2) *Regression*: Overall regression model for PTG at T2 included: caregiver sex, social support, self-efficacy, positive religious coping, negative religious coping. Overall model significant ($F(5, 128) = 7.03$; $R^2 = 0.15$) Positive religious coping made unique contribution to variance (β = 0.35)	Fair

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*Hungerbuehler et al. (2011)	Mothers and fathers of children with **severe illness** (Cancer & Diabetes) Cancer N = 64 Diabetes N = 62	Switzerland	Longitudinal Between group comparisons	To assess if medical, individual, and family-related characteristics predicts PTG in parents	PTG-I	Demographics, family functioning (Family Relationship Index), distress (BSI)	**Test:** T-tests, Regression *T-Test:* Mothers report higher PTG than fathers ($t(125) = 3.36$) Parents of children with cancer compared to parents of children with diabetes ($t(125) = 3.7$) *Regression:* Overall model included: cancer diagnosis, duration of time in hospital, female gender of parent, psychological distress, family relations. Overall model significant ($F = 10.88$, $R^2_{Adjusted} = 0.34$) Quality of family relations (β = 0.2), distress (β = 0.3); female parent (β = 0.21), cancer diagnosis (β = 0.31), length of initial hospital stay (β = -0.27) made a unique contribution to PTG	Fair
*Irie et al. (2021)	Parents of children with **cancer** and parents of children with **chronic childhood disease** Cancer N = 199 Chronic disease N = 120	Japan	Cross-sectional, observation Between group comparisons	Examine how PTG might be different with regards to cognitive processing among parents of children with cancer compared to those with chronic disease	PTG-I (Japanese version)	Demographics; PTS (IES-R), core beliefs (CBI), rumination (ERRI)	**Test:** T-Test, Correlation, SEM *Correlation:* Core belief re-examination in parents of children with cancer (r = 0.63) and in parents of chronic childhood disease (r=0.34). In chronic disease, deliberate rumination associated (r=0.46)	Fair

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Riva et al. (2014)	Parents of children who had a **stem cell transplant** N = 260	Sweden	Cross-sectional, observation	Investigate psychological outcomes in parents and whether psychological responses can be classified into clusters.	PTG-I	Anxiety and depression (HADS), burnout (Shirom-Malamed Burnout Questionnaire), PTS (PCL-C)	**Test:** Cluster analysis, correlation, ANOVA *Clusters:* Low distress / Low PTG High PTG Low distress / some PTG High distress *Correlation:* Overall PTG associated with anxiety (r = 0.15), PTS (r = 0.13) *ANOVA:* High distress cluster (no PTG) greater depression, burnout, anxiety and PTS, compared to other clusters High PTG group had higher anxiety and PTS compared to low distress clusters High distress cluster had lower perceived support, higher child health problems and job stress than other three clusters High PTG cluster had higher satisfaction with partner-relationship compared to other clusters Parents in the high PTG cluster reported the time before stem cell transplant and during the stem cell transplant was more stressful than the low distress/low PTG cluster	Good

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												(Statistical detail not reported)

Note: N = number of participants. *Indicates the study was included in the review by Kritikos et al. (2021). PTG-I = Posttraumatic Growth Inventory; PCL-C = Posttraumatic Stress Disorder Checklist; CHOP-SES = Children's hospital of Philadelphia Self-Efficacy Scale; MOS = Medical Outcomes Study Social Support Survey; LOT-R = Life Orientation Test-Revised; CESD = Centre for Epidemiological Studies Depression Scale; RCOPE = Brief Religious Coping Scale; CBI = Core Beliefs Inventory; IES-R = Impact of Events Scale Revised; BSI = Brief Symptom Inventory; ERRI = Event-Related Rumination Inventory; HADS = Hospital Anxiety and Depression Inventory; SES = Socioeconomic Status.

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Table 3

Characteristics of included observational studies (Other illnesses)

Reference	Sample (N and comparator, where applicable)	Country	Design	Aim	PTG Measure	Independent variable measure(d)	Significant Findings (P<0.05)	Quality
Burke & Hooper (2017)	Parents of children with **multiple food hypersensitivity** Food intolerant N = 241 Food Allergy (non-anaphylaxis) N = 32 Food allergy (anaphylaxis) = 21 Food allergy and intolerance (non-anaphylaxis) = 61 Food allergy and intolerance (anaphylaxis) = 35 No sensitivity (control) = 206	Australia	Cross-sectional, observation Between group comparison	To ascertain differences in the psychosocial profile of parents with food hypersensitive children	PTG-I	Comparing food allergy based on anaphylaxis, food intolerance, demographics	**Test:** ANOVA/MANCOVA Parental diagnosis of food sensitivity ($F(2, 488) = 5.02$) *ANCOVA:* Parents of food intolerant children and parents of children with combined hypersensitivities higher PTG than control ($F(3, 486) = 8.86$)	Good
*Byra et al. (2021)	Mothers of children with **cystic fibrosis** N = 144	Poland	Cross-sectional, observation	Analyse relationships between positive orientation and PTG, and mediation of coping	PTGI-I polish version	Demographics, coping (COPE), positive orientation (Positivity scale)	**Test:** Correlation Coping: focussing on the problem (r = 0.24), seeking emotional support (r = 0.48), acceptance (r = 0.24), religion (r = 0.18), positive orientation (r = 0.34)	Poor
*O-Hanlon et al. (2012)	Parents of children with **cleft lip / or palate**	UK	Quasi-experimental, between group comparison	To explore factors associated with parents' PTG and	PTG-I	Parental diagnosis of CL/P	**Test:** T-test / Mann Whitney U	Fair

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Parents with cleft lip diagnosis N = 27 Parents without cleft diagnosis (control) N = 27	the impact of a parental diagnosis

Note: N = number of participants. *Indicates the study was included in the review by Kritikos et al. (2021). PTG-I = Posttraumatic Growth Inventory; SES = Socioeconomic Status.

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Table 4

Characteristics of included RCTs

Reference	Sample	Design	Intervention	Control	Country	PTG measure	IV's / IV Measure	Primary outcomes	Quality
*Choi & Kim (2018)	Parents of children with **Cancer** Experimental N = 7 Control = 8	RCT Unblinded; 2 group	"Thank you, sorry, love" programme which aims to improve positive emotional interaction among family members	No intervention	South Korea	PTG-I (Korean Version)	Impact of intervention across 3 time points: Pre, post- and 10-week follow up	**Test:** ANCOVA Intervention allocation improved outcomes at post-test ($F(1, 11) = 9.39$, $p < 0.05$) and follow-up ($F(1, 9) = 7.39$, $p < 0.05$), when controlling for pre-test scores	High Risk
*Rosenberg et al. (2019)	Parents of children with **Cancer** 1:1 intervention = 26 Group intervention = 22 Control = 29	RCT 3 group, unblinded	Promoting Resilience in Stress Management – Parents (PRISM-P): a skills-based programme aimed at building resilience Three treatment arms: (1) 1:1 intervention (2) Group intervention (3) Treatment as usual	TAU	USA	BFS	Delivery of intervention (PRISM-P): 1:1, group format, or TAU. Time: baseline, 3-months post-intervention	**Test:** Intention-to-treat analysis 1:1 intervention increased PTG compared to TAU ($\beta = 0.5$, $p<0.001$) No other outcomes significantly associated	Low risk

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Rosenberg et al. (2021)	Parents of children with **Cancer** 1:1 intervention = 26 Group intervention = 22 Control = 29	RCT 3 group, unblinded.	PRISM-P Three treatment arms: (1) 1:1 intervention (2) Group intervention (3) Treatment as usual	TAU	USA	BFS	Delivery of intervention (PRISM-P): 1:1, group, TAU Time: baseline, 3- and 6-months post-intervention	No significant difference in PTG between baseline and 6-month outcomes between 1:1 intervention and TAU (p=0.09) No difference in scores between baseline and 6-months between TAU and group intervention (p=0.11)	Low risk
*Lindwall et al. (2014)	Parents of children undergoing **stem cell transplant** Child = 58 Parent and child = 57 Control = 56	RCT (Randomisation method not reported) 3 group	Intervention aimed at reducing distress and increasing positive emotions through massage therapy and humour 3 treatment arms: 1) Child only intervention 2) Child and parent intervention 3) Control	TAU	USA and Canada	BFS	Impact of intervention across time (baseline to 24 weeks)	**Test:** ANCOVA Parents benefit finding increased over time (F = 12.4) No significant difference across treatment arms (F = 0.9), or treatment and time interaction (F = 0.8)	High risk

Note: N = number of participants. *Indicates the study was included in the review by Kritikos et al. (2021). IV = Independent Variable; TAU = Treatment as Usual; PTG-I = Posttraumatic Growth Inventory; BFS = Benefit Finding Scale

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Sample size and Study Characteristics

Population. Studies were published between 2007 and 2021. Geographical locations included: Iran, Turkey, Sweden, Switzerland, Poland, Korea, Japan, Australia, UK, USA, and Canada. The overall sample was comprised of 3520 parents (excluding 233 comparator parents of children without CPI). Sample sizes varied between 15 (Choi & Kim, 2018) to 599 (Burke & Hooper, 2017). Of those which reported gender, 2869 were mothers and 449 were fathers.

Most studies were in oncological samples (N=19). Other CPIs included: cystic fibrosis (Brya et al., 2017), food intolerance/hypersensitivity (Burke & Hooper, 2017), diabetes (Hungerbuehler et al., 2011; Irie et al., 2021), arthritis (Irie et al., 2021), cleft lip/palate (O'Hanlon et al., 2021) stem cell transplant survivors (Chardon et al., 2021, Riva et al., 2014), and mixed samples (Cadell et al., 2014; Hungerbuehler et al., 2011). Of those studies that reported the child's age and time since diagnosis, children were on average 10.06 (*SD* = 3.9) years old and 5.13 (*SD* = 1.75) years had passed since diagnosis.

Design. Of the twenty-five papers reporting observational designs, three were longitudinal (Barakat et al., 2020; Hungerbuehler et al., 2011; Weber, 2014) – the remaining 22 were cross-sectional. Four RCTs were included (Choi & Kim, 2018; Lindwall et al., 2014; Rosenberg et al., 2019; Rosenberg et al., 2021): two of them reported on the same sample of participants (Rosenberg et al., 2019; Rosenberg et al., 2021) at different time points. Two pairs of papers reported on the same sample (Kim, 2015; Kim, 2017; Turner-Sack, 2007; Turner-Sack et al., 2015). All studies used questionnaires or health records to obtain information.

Measures. Twenty-four papers used the Posttraumatic Growth Inventory (PTG-I; Tedeschi & Calhoun, 1996) or a validated translation to assess PTG; 23 employed

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observational designs and one was a RCT (Choi & Kim, 2018). The remaining five papers used the Benefit Finding Scale (BFS; Antoni et al., 2001) – three of which were RCTs (Lindwall et al., 2014; Rosenberg et al., 2019; Rosenberg et al., 2021) and two were observational (Bender, 2010; Gardner et al., 2017).

Assessment of bias and quality

Twenty-five papers were assessed using the QATOCCS (NIH, 2014), the majority (>60%) being assessed as fair. Weaknesses in observational studies were attributed to cross-sectional design. The remaining four studies were assessed using the RoB2; two were high risk (Choi & Kim, 2018; Lindwall et al., 2014) and two papers (describing the same study) were low risk (Rosenberg et al., 2019; Rosenberg et al., 2021). A second reviewer (PW) completed independent ratings. Percentage agreement between reviewers was 80%. Cohen's Kappa was 0.7 ($k=0.71$, $p<0.01$), indicating substantial agreement (McHugh, 2012). See Tables 1-4 for study details.

Study Findings and Narrative Synthesis

Parental demographics. Ten papers investigated parental role in relation to PTG (Bender, 2010; Dirik, 2018; Hong et al., 2019; Hungerbuehler et al., 2011; Nakayama et al., 2016; Chardon et al., 2021; Hullmann et al., 2014; Hullman, 2014; Irie et al., 2021; Weber, 2014). Evidence from fair quality studies reporting predominantly on parents of children with cancer was mixed. Some suggested being a mother, compared to a father, increased PTG; others failed to find a relationship. Best available evidence in oncological samples suggests there is no relationship between gender and PTG (Weber, 2014).

Evidence from ten papers (reporting on 9 studies) of mixed methodological rigour failed to find a significant relationship between socioeconomic status (SES) and PTG (Behzadi et al., 2018; Barakat et al., 2020, Burke & Hooper 2017; Gardner et al., 2017;

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Hullmann et al., 2014; Hullman, 2014; Michel et al., 2010; Nakayama et al., 2016; Turner-Sack, 2007; Kim, 2015). Although the majority were conducted on oncological samples, results were consistent for parents of children with food hypersensitivity (Burke & Hooper, 2017). Therefore, SES is unlikely to be related to PTG in parents of children with CPI. However, the strength of this conclusion is limited by the heterogeneity of SES measure including parental income/employment (Burke & Hooper, 2017; Hullmann, 2013), education (Behzadi et al., 2018), postcode (Michel et al., 2010) or a combination (Gardner et al., 2017; Kim, 2015).

Chronic illness characteristics. Best available evidence suggests parents' PTG may vary within diagnostic subtypes of food hypersensitivity (Burke & Hooper, 2017). Some evidence from fair quality studies in parents of children with cancer failed to find differing levels of PTG across diagnostic groups (Hong et al., 2019; Hullmann et al., 2014; Hullmann, 2014; Michel et al., 2010; Nakayama et al., 2016; Irie et al., 2021; Kim, 2015). However, when comparing cancer with other CPIs, cancer diagnosis may be associated with greater PTG (Hungerbuehler et al., 2011).

Time since diagnosis was explored across eight papers (reporting on seven studies) (Bender, 2010; Michel et al., 2010; Oginska-Bulik et al., 2016; Turner-Sack, 2007; Turner-Sack et al., 2015; Irie et al., 2021; Weber, 2014; Riva et al., 2013). Best available evidence was conflicted: in parents of children with cancer where 4.7 years had lapsed, time since diagnosis was positively associated with PTG (Weber, 2014). Contrastingly, a cluster analysis failed to find a significant difference between time elapsed across high and low PTG clusters (Riva et al., 2014). Time elapsed was comparable (5.5 years). However, this study included a sample of children with mixed illnesses (cancer, sickle cell disease and osteoporosis) but does not report diagnostic composition of clusters, limiting conclusions regarding diagnosis type, time lapsed, and parental PTG.

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Psychosocial variables

Social support. Good quality studies report perception of social support and utilisation of support groups were associated with PTG (Weber, 2014; Riva et al., 2015). There was tentative evidence from a fair quality study on parents of children with cancer that quality familial relationships were predictive of greater PTG (Hungerbuehler et al., 2011). The association of social support with subsequent PTG was consistent across diagnostic groups including cancer (Weber, 2014), diabetes (Hungerbuehler et al., 2011) and parents of children who underwent stem cell transplant (Riva et al., 2014).

Mental Health. Tentative evidence from fair quality cross-sectional studies suggests PTS and PTG are not linearly related across samples of mixed illness (Irie et al., 2021; Chardon et al., 2021) and cancer (Hullmann, 2013; Michel et al., 2010; Nakayama et al., 2016). However, best available evidence, from a longitudinal study in oncological samples found a curvilinear relationship was significantly better at explaining the relationship between PTS and PTG than a linear relationship (Weber, 2014). Moderate PTS may be associated with PTG, but cross-sectional studies did not report exploration of a curvilinear relationship.

General distress was explored across three fair quality papers with mixed findings across groups (Cadell et al., 2014; Hungerbeulher et al., 2011; Kim, 2015). In oncological samples, low and high levels of parental distress were associated with greater PTG (Kim, 2015; Hungebeuhler et al., 2011). In mixed illnesses, greater distress was associated with PTG (Cadell et al., 2014). However, Cadell and colleagues (2014) assessed distress by aggregating scores of depression and burden measures, which may explain this.

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Best available evidence suggests anxiety (measured by the Hospital Anxiety and Depression Scale; HADS; Snaith & Zigmond, 1986) in parents of children with mixed illness is significantly associated with PTG (Riva et al., 2014). Similarly, in parents of children with cancer, state anxiety was positively associated with PTG but was not statistically significant (Nakayama et al., 2016). Trait anxiety was negatively associated with PTG (Nakayama et al., 2016). However, this study was fair quality and conclusions may be constrained by lack of methodological rigour. Depression and burnout are unlikely to be related to PTG in parents of children with mixed illness (Riva et al., 2014).

Tentative evidence suggests that hope, optimism and wellbeing might be related to PTG across mixed illnesses (Hullmann et al., 2014, Gardner et al., 2017; Kim, 2017). Contrasting evidence from a study of poor quality suggests PTG and parent wellbeing are not related (Turner-Sack, 2007; Turner-Sack et al., 2015). Methodological limitations of these studies reduce robustness of conclusions regarding positive mental health outcomes and PTG.

Cognitive processing. There is indication that illness perception in oncological samples influences PTG, though the complexities within the relationship is unclear (Hullmann, 2013; Michel et al., 2010). Results were mixed, with heterogenous methods of capturing illness perception. One study (Hullmann, 2013) found a positive non-significant relationship with illness uncertainty. Another analysed individual scale items finding only one item (emotional impact of the illness) to be significant (Michel et al., 2010).

Deliberate rumination may contribute to PTG (Hong et al., 2019; Kim, 2017; Irie et al., 2021). Irie and colleagues (2021) found that deliberate rumination was only associated with greater PTG in parents of children with chronic disease – not cancer. Contrasting findings arose regarding parents of children with leukaemia, where a positive association was found with deliberate rumination (Hong et al., 2019). Both studies failed to find a significant

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relationship between PTG and intrusive rumination and were fair in quality. One study suggested deliberate rumination may link core belief re-examination with PTG (Kim, 2017)

Core belief re-examination may be positively associated with PTG in parents of children with cancer (Hong et al., 2019; Irie et al., 2021). There was tentative evidence for an indirect relationship between core belief disruption and PTG via deliberate rumination (Hong et al., 2019). However, all studies were fair quality and thus results should be interpreted cautiously.

Studies of poor and fair methodological rigour reported mixed results regarding coping (Chardon et al., 2021; Gardner et al., 2017; Byra et al., 2021; Turner-Sack, 2007; Turner-Sack et al., 2015). Best available evidence suggested positive religious coping is associated with PTG and negative religious coping is not (Gardner et al., 2017; Chardon et al., 2021). Other associated coping strategies included active and emotional coping (Gardner et al., 2017). Results from a poor-quality study on parents of children with cystic fibrosis suggested emotional, acceptance and religious coping were associated with PTG (Byra et al., 2021). On the other hand, Turner-Sack (2007) and Turner-Sack et al. (2015) found no significant relationship between coping and PTG. All studies used the COPE (Carver et al., 1989), or brief religious coping scale (RCOPE; Pargament et al., 2003) to conceptualise coping.

***Religion / Spirituality*.** Conceptualisation of religion/spirituality varied across studies. Some measured it as a coping style, others as a demographic variable. Five papers of fair quality explored religiosity as a demographic variable (Cadell et al., 2014; Czyzowska et al., 2021; Hong et al., 2019; Irie et al., 2021; Kim, 2015). For parents of children with cancer, evidence suggests religiosity is positively associated with PTG (Czyzowska et al., 2021; Hong et al., 2019; Kim, 2015). Conversely, in parents of children with mixed illnesses, no significant relationship was found (Cadell et al., 2014; Irie et al., 2021).

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Interventions. Four papers examined the impact of interventions on parental PTG using RCTs – two papers reported on the same intervention (Rosenberg et al., 2019; Rosenberg et al., 2021). Best available evidence reported on an intervention aimed to develop resilience through mindfulness, problem solving, cognitive reappraisal and meaning making. When delivered one-to-one, PTG increased compared to usual care (Rosenberg et al., 2019). Improvements were not sustained at 6-month follow-up (Rosenberg et al., 2021).

Two papers of high risk reported conflicting evidence regarding the usefulness of interventions in facilitating PTG (Lindwall et al., 2020; Choi & Kim, 2018). Both indicated PTG increases over time; one study failed to find a significant effect of a psychoeducational intervention (Lindwall et al., 2020), the other reported increases in PTG at post-test and follow-up resulting from an intervention encouraging familial emotional interaction (Choi & Kim, 2018).

Discussion

The aim of this review was to explore the correlates of PTG among parents of children and adolescents with CPIs. This review extended and clarified previous reviews (Kritikos et al., 2021; Picoraro et al., 2014), exploring parental PTG in a narrower sample and applying a more robust evaluation of study quality. Results from best available evidence suggests PTG may increase across time and be influenced by perception and quality of social support. Moderate levels of PTS and elevated anxiety were associated with PTG. Parent gender and SES were unlikely to be related. Studies of good methodological rigour were limited in number, restricting synthesis based on best available evidence. Tentative evidence aligned with cognitive models of PTG (Tedeschi & Calhoun, 2004), suggesting positive religious coping and cognitive processes (illness perception, deliberate rumination, core belief re-examination, coping) may contribute to PTG. Interventions which facilitate

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mindfulness and cognitive reappraisal may encourage parents' PTG (Rosenberg et al., 2019; Rosenberg et al., 2021); further research is needed to explore how these effects are maintained over time. Robustness of conclusions are constrained by methodological limitations and heterogeneity.

This review did not find a consistent relationship between parent gender and PTG. The ability to draw a robust conclusion based on this synthesis is limited as the number of mothers far outweighed fathers. Inconsistencies in gender differences is mirrored in the broader literature (Jang, 2005). Meta-analyses indicate a trend of women reporting greater PTG than men (Vishnevsky et al., 2010). Possible gender differences in cognitive processing, namely, women perceiving situations as more threatening (Olff et al., 2007), may lead to greater core belief disruption and subsequent need for redevelopment, hence greater PTG (Calhoun & Tedeschi, 2006).

SES was not found to be associated with PTG in parents of children with chronic illnesses, regardless of quality and diagnostic group. However, SES was often measured using demographic questionnaires. Conceptualisation varied from parental education, employment, income and postcode – reducing validity. Furthermore, difficulties accessing and participating in health research in lower SES backgrounds means these individuals are likely underrepresented (Hussain-Gambles et al., 2004). Since SES has been identified as a factor of disparities in health outcomes (Shavers, 2007), future research would benefit from using a standardised measure of SES (e.g., Hollingshead Index; Hollingshead, 1975), when exploring relationships with PTG.

The results of this review indicate a possible temporal course of PTG. Theoretically, it is suggested that schema are meaningfully reconstructed across time (Joseph et al., 2005). However, longitudinal studies were limited in number and only conducted for parents

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of children with cancer in the USA. Similar conclusions cannot be drawn for parents of children with other chronic illnesses or residing in different countries.

Cross-sectional studies attempted to explore the temporal course of PTG by measuring association with time elapsed since illness onset. In parents of children with cancer, there was no significant correlation between the two variables, despite having similar durations of time elapsed since diagnosis across different studies.. It has been posited that PTG may taper with time and different domains of PTG may be significant with varying time (Fraizer et al., 2001). However, the robustness of this hypothesis is limited by the dearth of longitudinal studies (Tedeschi & Calhoun, 2004) and research exploring PTG years after the event, limiting understanding in the immediate aftermath. Future research would benefit from measuring PTG across multiple time points.

Illness characteristics (e.g., severity of illness), were also explored, but results were inconsistent. Previous reviews (e.g., Kritikos et al., 2021) suggest differences between medical conditions may be attributable to level of life threat. However, in the current review, there was a lack of studies comparing across diagnostic groups (compared to subtypes of diagnoses) to test this. However, there was tentative evidence to suggest subjective trauma experience and cognitive appraisals may influence PTG more than objective severity (Linley & Joseph, 2004; Picoraro et al., 2014).

Aligned with previous reviews (Picoraro et al., 2014), there was evidence that parents who perceive their child's illness as more severe experience greater PTG (Hullmann, 2013; Michel et al., 2010). Leventhal's self-regulation theory suggests specific cognitive representations are developed to cope with the onset of a physical illness (Leventhal et al., 1980; Leventhal et al., 1987). Greater illness perception may require more intensive cognitive processing, increasing opportunities to ascribe positive meaning (Diefenbach & Leventhal, 1996; Leventhal et al., 1997; David et al., 2021). However, many studies

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assessing illness perception were fair quality and used heterogenous measures and so this finding should be interpreted cautiously.

Core belief disruption and re-examination may be positively associated with PTG in parents of children with cancer (Hong et al., 2019; Irie et al., 2021). Pre-existing schemas need to be re-examined to accommodate or assimilate trauma information, resulting in growth. This may be accomplished through rumination (Picoraro et al., 2014), which may mediate the relationship between core belief re-examination and PTG (Hong et al., 2019). Across the literature, intrusive and deliberate rumination have been associated with PTG (Tedeschi & Calhoun, 2004; Taku et al., 2009; Picoraro et al., 2014); stronger associations with deliberate rumination aligned with results of this review. Contrasting to Picoraro et al. (2014), no significant relationship was found between intrusive rumination and PTG. This may be attributable to the time which had lapsed since diagnosis for this sample averaging five years; intrusive rumination may be more common in the immediate aftermath of trauma (Rider et al., 2019), with deliberate rumination increasing across time (Taku et al., 2009).

Trauma processing is a highly emotive process, which may be part of what makes it transformative (Tedeschi & Calhoun, 2004). In contrast to Kritikos et al. (2021), the current review did not find evidence of a linear relationship between PTS and PTG. However, these studies used cross-sectional designs and did not report exploration of a curvilinear relationship. Indeed, best available evidence suggests PTS and PTG may be curvilinearly related (Weber, 2014). A degree of distress may be required to disrupt core beliefs and stimulate growth (Tedeschi & Calhoun, 2004). If this distress becomes exceedingly severe, this may increase avoidance and inhibit deliberate rumination required for PTG (Chan et al., 2011).

Anxiety may be associated with PTG in parents of children who underwent stem cell transplant (Riva et al., 2014) and cancer (Nakayama et al., 2016), aligning with previous

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reviews (Kritikos et al., 2021). Literature suggests a degree of emotional engagement and recognition of change resulting from trauma is necessary for PTG to occur (Collicutt-McGrath & Linley, 2006). As a result, anxiety may increase as the individual comes to terms with the long-term consequences of chronic illness (Tyerman & Humphrey, 1983) or illness uncertainty (McDonnell et al., 2018).

Social support may be beneficial in dealing with the emotions of processing trauma (Linley & Joseph, 2004). Several studies in this review reported a positive association between social support and PTG (Hungerbuehler et al., 2011; Kim, 2017; Weber, 2014; Riva et al., 2015). However, there are mixed reports regarding the relationship between social support and PTG more broadly (Schroevers et al., 2010), possibly attributable to the conceptualisation of social support within the psychological literature. For example, some studies measure size of social networks, others assess the usefulness of social support. In the current review, perception of, and better-quality social relationships were positively associated with PTG (Hungerbuehler et al., 2011; Kim, 2017) and this was consistent across different CPIs.

Coping styles are commonly cited correlates of post-traumatic reactions (Peters et al., 2021). Contrary to Picoraro et al. (2014), this review found positive religious coping was predictive of PTG in primarily oncological samples (Chardon et al., 2021; Gardner et al., 2017). This may be attributable to the overlap in concepts of religious coping scales and religious/spirituality subscales of PTG measures. However, similar results were found when religion/spirituality was measured as a demographic factor in parents of children with cancer (Czyzowska et al., 2021; Hong et al., 2019; Kim; 2015), but not for parents of children with mixed illnesses (Cadell et al., 2014; Irie et al., 2021). These conflicting results across diagnostic groups may be due to heterogeneity in measurement. Conceptualisation of religiosity as a coping strategy revealed negative religious coping had no association with PTG (Gardner et al., 2017; Chardon et al., 2021), consistent with the broader literature

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(Greber et al., 2011). When religiosity is measured as a demographic characteristic, it is impossible to establish whether it is helpful or a hindrance. Nevertheless, for parents of children with cancer, when core beliefs are disrupted by illness onset, religiosity may act as an important framework for emotional processing and PTG (Lechner et al., 2006).

Finally, interventions aimed at building resilience, stress management, meaning making and cognitive restructuring may facilitate PTG in parents of children with cancer (PRISM-P; Rosenberg et al., 2019; Rosenberg et al., 2021). Aligning with adult oncological literature, stress management through mindfulness is one of the most effective interventions for facilitating PTG (Li et al., 2020). This may be via the process of deliberate rumination, enabling individuals to establish meaning and process trauma in a structured way. As previously discussed, deliberate rumination is a likely cognitive processing technique of parents of children with CPIs. However, the results of the PRISM-P trial were not sustained at follow-up and are only applicable to parents of children with cancer. Further research is needed to explore how to maintain these benefits across time.

Strengths and Limitations

This review explores correlates of PTG in parents of children with CPIs specifically, making a unique contribution to the evidence base. Relative to previous reviews (E.g., Kritikos et al., 2021; Picoraro et al., 2014) the methodological rigour of this review was strong, using robust quality assessment tools (Ma et al., 2020), and stratifying results based upon best available evidence. Quality ratings were completed by two individuals (AP & PW); rate of agreement was acceptable (80%; Belur et al., 2018).

Whilst methodological rigour was a strength, it must be noted that many included studies were fair quality. Low quality studies were also included which may increase bias. Low methodological rigour was primarily attributable to cross-sectional designs and attrition,

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limiting causal inferences. Secondly, factors which were explored in association with PTG were assessed using heterogenous measurements. For example, social support is a nuanced construct that was measured in various ways, including perception and network size. Additionally, PTG was assessed with various measures. This makes it difficult to draw conclusions about what specifically is associated with PTG in parents of children with CPIs.

This review may be limited by bias. For example, reviewer bias cannot be ruled out, although attempts were made to mitigate this through second- and third- reviewers. While the overall sample was relatively large, the number of female parents outweighed those of males and most studies were conducted in the USA and Canada. Approximately 50% of total papers were on parents of children with cancer, reducing generalisability of results.

Moreover, the heterogeneity in CPI type (e.g., cancer vs food allergy) weakened conclusions. The nature of these conditions is variable; illness characteristics and treatment characteristics, such as intrusiveness of medical procedures, may influence trauma experience (Sultan et al., 2016). Other factors such as prognosis (Norberg et al., 2012) and the child's distress (Klassen et al., 2012) may contribute to post-traumatic experiences. Indeed, the results of this review suggest illness characteristics and perception can influence subsequent PTG, making it difficult to draw conclusions regarding PTG in parents of children with CPI as a general population. Overall, the degree of heterogeneity across studies prevented meta-analysis.

Implications for Research and Clinical Practice

Collectively, parents of children with CPI may benefit from psychological interventions aimed at enabling deliberate rumination and core belief re-examination (via cognitive restructuring, e.g., Rosenberg et al., 2020). Interventions should be person-centred, simultaneously acknowledging the potential for psychological growth, as well as

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psychological distress such as elevated anxiety. Stress management interventions (e.g., Rosenberg et al., 2020) may be of particular use for this population. Future research should aim to explore the efficacy of mindfulness in reducing stress for parents of children with CPI, as it has been found effective in reducing stress and facilitating PTG in adults with cancer (Li et al., 2020). Moreover, positive psychological outcomes resulting from psychosocial interventions for parents of children with CPI may be improved by promoting social support, for example, using group interventions run by mentors with lived experience (Tulip et al., 2020). This could provide parents with a safe and nurturing environment to deliberately ruminate and re-examine core beliefs with supportive others. However, further research is required to establish the types of social support which may be of benefit to parents of children with CPI.

Due to the limited sample of men and possible gender influence on PTG, future research should aim to explore PTG in fathers. A more consistent measure of capturing markers of health inequalities (e.g., SES) could increase generalisability. PTG should be explored across more countries, SES backgrounds, and CPI types (e.g., epilepsy). Varying symptomology, prognosis, and treatment across different types of CPI may influence illness perception (Leventhal et al., 1980), which was associated with PTG in this review. Future reviews may benefit from exploring narrower populations of CPI's independently (e.g., cancer, diabetes etc) to improve validity of conclusions.

The results of this review align with prior research which indicate PTG may evolve across time according to the presences and/or absence of different contextual factors (Shakespeare-Finch & Lurie-Beck, 2013). As time seems particularly pertinent in post-traumatic reactions in parents of children with CPI (e.g., secondary post-traumatic events which occur following the acute trauma) (Picoraro et al., 2014; Kazak et al., 2006), future studies would benefit from measuring PTG across multiple time points to establish the evolution of PTG in this sample.

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Finally, future research would benefit from using more homogenous outcome measures to assess factors associated with PTG. This would allow completion of a meta-analysis, providing a more objective appraisal of the evidence, compared to narrative review, as used in this study. Many studies included in this review were carried out in the USA and Canada. Future research should aim to include more diverse samples of diagnostic groups and in different countries to understand cultural influence on PTG.

Conclusions

Best available evidence suggests PTG in parents of children with CPI may increase across time. Making sense of a child's CPI and, indeed, perceiving benefit, may be highly emotive leading to increases in anxiety and PTS. Moderate levels of PTS may catalyse PTG, whilst social support and religious coping may provide adaptive ways of managing distress. SES and parent gender were not found to be associated with PTG, but sample limitations make it difficult to conclude with certainty. Tentative evidence aligned with cognitive theories of PTG (Tedeschi & Calhoun, 2004): parents who perceive their child's illness as more severe may experience greater core belief disruption, which was associated with PTG. Deliberate rumination was associated with greater PTG and might influence the relationship between core belief disruption and PTG. PTG may be facilitated through interventions targeting cognitive reappraisal and encouraging deliberate rumination but further research should explore how benefits can be maintained. Conclusions are limited by lack of longitudinal designs and heterogeneity of measures used to assess correlates of PTG. Future research exploring the temporal development of PTG is warranted, including greater involvement of fathers, broader diagnostic groups and geographical locations.

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Chapter Three: Bridging Chapter

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Chapter Three: Bridging Chapter

The systematic review in Chapter Two investigated the correlates of posttraumatic growth (PTG) in parents of children and adolescents with chronic physical illnesses. Overall, results aligned with previous reviews and cognitive theories of PTG (Tedeschi & Calhoun, 1996; Picoraro et al., 2014; Kritikos et al., 2021). It was tentatively hypothesised that the more severe parents perceived their child's illness to be, the more core belief disruption would occur and the greater PTG would be. The relationship between parental posttraumatic stress (PTS) and PTG was complex. Some studies failed to find a relationship, whilst others suggest the relationship may be nuanced – with moderate levels of PTS being associated with greater PTG compared to extremely high or low levels. Perhaps, greater PTS severity might inhibit cognitive processes associated with PTG, as the results of this review suggest, a degree of deliberate rumination is required for re-establishment of shattered schema (i.e., PTG). This course of interpreting, processing, and making sense of a child's chronic physical illness is likely to be highly emotive, perhaps explaining the association between mental health symptoms and PTG in parents. Thus, the use of effective coping strategies, such as drawing upon good quality social support and religiosity is likely to facilitate PTG. Contextual factors such as time were also associated with greater PTG, and there was emerging evidence for psychological interventions targeting cognitive reappraisal in enhancing PTG.

However, these conclusions must be interpreted cautiously due to several limitations. Namely, the inclusion of low-quality studies; lack of longitudinal studies; use of heterogenous measurements; and underrepresentation of certain populations within the overall sample. For example, the majority of studies were conducted in the USA and Canada and over 80% of the total sample were mothers. Moreover, the sample was predominantly parents of children with cancer. Other diagnostic groups included cystic fibrosis, food hypersensitivity, arthritis, cleft lip palate and individuals who underwent stem cell transplant for conditions such as sickle cell disease, but these were limited in number. Thus, future research should

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aim to explore PTG experiences in fathers, different geographical locations and across broader diagnostic groups.

Although the World Health Organisation (WHO, 2021) recognises acquired brain injury (ABI) as a chronic physical illness, the review highlighted the dearth of research exploring PTG in parents of children with ABI. Research highlights the negative psychological impacts of caring for a child with ABI (Perlesz et al., 2000; Riley, 2007; Stacin et al., 2008; Tyerman et al., 2017). However, the possibility of PTS is yet to be explored within this population. Some theories of PTG, and indeed, the results of the review, suggest a degree of distress is necessary to disrupt schema and stimulate PTG (Tedeschi & Calhoun, 1996; Zebrack et al., 2015; David et al., 2021).

Common predictors of PTS and PTG have been identified and include trauma severity (Brown et al., 2003; Kassam-Adams et al., 2009; Hungerbuehler et al., 2011) and time since traumatic event. Greater time elapsed since the traumatic event has been negatively associated with PTS in parents of hospitalised children (Franck et al., 2015), and predictive of growth in parents of children with chronic physical illness, as indicated in the systematic review. Secondly, coping styles are frequently associated with both PTS and PTG (Greening & Stoppelbein, 2007; Brown et al., 2003; Peters et al., 2021), with avoidance being associated with PTS, reducing opportunities to meaningfully process trauma-related information (Turner-Sack et al., 2016; Westgate, 2019). Approach-oriented coping (e.g., acceptance) may provide opportunities for the individual to process and establish meaning from trauma experiences and therefore might contribute to PTG (Pineles et al., 2011; David et al., 2021). Finally, social support may buffer PTS and facilitate PTG by providing a safe environment to meaningfully process and construct narrative regarding the trauma (David et al., 2021; Swartzman et al., 2017).

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A better conceptualisation of these factors in the relationship between PTS and PTG in parents of children with ABI is important, given familial functioning and distress is predictive of a child's rehabilitative outcomes (Wade et al., 2001; Verhaeghe et al., 2005). Evidence-based interventions could be tailored to reduce distress and promote adjustment in parents following their child's ABI (Smith et al., 2014). To this end, the empirical study in the following chapter will explore whether a relationship exists between PTS and PTG in parents of children with ABI, and the possible influence of acceptance-, avoidance-, and social-support coping in relation to PTS and PTG, independently.

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Chapter Four: Empirical Study

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Is there a relationship between posttraumatic stress and posttraumatic growth in parents of children with acquired brain injuries?

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Abstract

A paediatric acquired brain injury (ABI) can endanger life and impact a child's development. Negative psychological impacts on parents have been documented, but there is a gap in the literature exploring posttraumatic reactions. The aim of this research was to explore whether a relationship exists between posttraumatic stress (PTS) and posttraumatic growth (PTG) in parents of children with ABI, and the association of acceptance-, avoidance-, and social support-coping in relation to PTS and PTG, independently. Forty-nine parents completed an online survey of quantitative measures of PTS, PTG, coping, social network size and demographics. A correlation analysis and quadratic regression suggested no linear or curvilinear relationship between PTS and PTG. Regression analyses indicated only avoidance-coping made a significant contribution to variance in PTS, and only acceptance-coping contributed to PTG. Social support was not significant in either model. PTS and PTG appear to be distinct constructs in parents of children with ABI, although both may be influenced by coping styles. The results and conclusions of this study are limited by the sample size, statistical power, cross-sectional design and conceptual overlap between dimensions of PTS, PTG and coping. Future research should recruit a more diverse sample, exploring the multidimensional relationship between PTS, PTG and coping, longitudinally.

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Introduction

An acquired brain injury (ABI) is a brain injury caused by an accident or illness after a period of normal development (Headway, N.d.). In the United Kingdom, 200,000 children acquire brain injuries each year (Neurological Alliance, 2003), with the World Health Organisation ranking brain injury as a leading cause of disability and mortality in children worldwide (WHO, 2006). ABIs can lead to physical, cognitive, behavioural, psychological, and social changes (Savage et al., 2005), divert typical developmental trajectories and endanger life (Brown et al., 2015). However, advances in acute medical care mean children are likely to survive the injury and reach adulthood.

Parents assume key roles in rehabilitation for children with ABIs (Minnes et al., 2010). Parent-implemented rehabilitation programmes have been found superior to clinician-delivered programmes (Braga et al., 2005). Rehabilitation for children may be ongoing throughout their life (Jordan & Linden, 2013), prolonging parents responsibilities (Minnes et al., 2010). Parent's engagement with rehabilitative programmes may be impacted by their psychological wellbeing (Brown et al., 2013; Bivona et al., 2020)

Disturbances from paediatric ABIs can cause psychological and adjustment difficulties for parents (Yeates et al., 2004), including distress, (Prigatano & Gray, 2007), anxiety (Perlesz et al., 2000), depression (Riley, 2007), burden (Stancin et al., 2008), social isolation (Tyerman et al., 2017) and relational difficulties (Rivara et al.,1992). Whilst organic injury severity can influence cognitive and physical outcomes, psychosocial factors such as familial distress and functioning have been associated with rehabilitative progress (Anderson et al., 2005). Healthy family functioning can improve outcomes for the individual with an ABI (Wade et al., 2001; Verhaeghe et al., 2005). As ABIs can be life-threatening and suddenly disrupt family functioning, negative psychological impacts are unsurprising. Nevertheless, posttraumatic stress (PTS) is yet to be explored within this population.

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PTS in Paediatric Medical Events

PTS describes psychological symptoms including hyperarousal, avoidance, and flashbacks (Ehlers & Clark, 2000) following a traumatic event (i.e., events which may lead to actual, or threatened death, serious injury or violence; American Psychiatric Association, 2013). PTS may be considered a 'disorder', (post-traumatic stress disorder,PTSD), when symptoms exceed or meet a certain diagnostic threshold. Parents can experience PTS following their child's diagnosis of cancer (Kazak et al., 1997), brain tumour (Westgate, 2019), injuries (Kassam-Adams et al., 2009) and intensive care admissions (Colville & Cream, 2009). Paediatric ABI's often bring children and their families into healthcare settings under adverse and life-threatening circumstances and may be perceived as traumatic.

One model of PTS suggests our cognitive frameworks (schema) might be 'shattered' due to incongruency between existing schema and trauma-related information (Janoff-Bulman, 1992). This can disturb contextualisation of trauma memories, leading the individual to perceive the previous threat as posing current threat (Ehlers & Clark, 2000). For parents of children who have experienced medical stress, the experience of PTS may be different. The Paediatric Medical Traumatic Stress model (Kazak et al., 2006) posits that beyond the immediate aftermath of the medical event, threat exposure can continue from subsequent medical treatments.

Posttraumatic growth (PTG) in paediatric medical events

Holistic conceptualisations of posttraumatic reactions also acknowledge positive change such as PTG (Joseph & Linley, 2005). PTG describes positive psychological development following the struggle with trauma, occurring across five domains: appreciation for life, relating to others, personal strength, new possibilities, and spiritual growth (Tedeschi & Calhoun, 1995). When schemas are challenged, there is scope for redevelopment – rebuilding or assimilating the trauma information, making them more resilient to 'shattering' (Tedeschi & Calhoun, 2004).

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Like PTS, PTG in parents of children with paediatric illness is considered unique. Extending upon Tedeschi and Calhoun's theory of PTG (1995), Picoraro et al. (2014) suggest a model of PTG for parents and children following paediatric illness which emphasises the role of social support (Picoraro et al., 2014). The model also involves a temporal component: events following the initial trauma, such as rehabilitative surgery, may influence posttraumatic reactions in this population.

Parents of children with cancer (Barakat et al., 2006), and those who have been admitted to intensive care (Colville & Cream, 2009), report PTG. Similarly, caregivers of adults with ABI report finding meaning from brain injury (Hallam & Morris, 2014), with PTG reducing negative psychological outcomes and enhancing wellbeing for some (Kinsella et al., 2015). Qualitative studies in parents of children with ABI report similar findings: parents describe finding meaning in their loss, focussing on their child's newfound qualities including strength in the face of adversity (Yehene et al., 2021). PTG is yet to be explored quantitatively in this population.

PTS and PTG

Whilst some models imply trauma is required for PTG, there is uncertainty regarding the relationship between PTS and PTG. Some suggest the two concepts are related (Marziliano et al., 2020), whilst others suggest they are independent (Shand et al., 2015). In medical trauma populations the relationship between PTS and PTG may be more complex: a meta-analysis found a weak-to-null relationship in samples with ill-health (Shakespeare-Finch & Laurie-Beck, 2014). This may be owing to methodological limitations including exploration of single dimensions of PTS and PTG (Morris et al., 2005), or analyses only suitable for detecting a linear relationship (Shakespeare-Finch & Laurie-Beck, 2014). The relationship may be curvilinear (Helgeson et al., 2006). Events need to be sufficiently traumatic to 'shatter' schema, but extremely traumatic events may increase PTS which could

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inhibit PTG (Tedeschi & Calhoun, 2004). Positive linear and curvilinear relationships between PTS and PTG have been reported in parents of children with cancer (Weber, 2014) and those who have been admitted to intensive care (Colville & Cream, 2009).

A small number of studies have explored the psychosocial factors which influence both PTS and PTG, with the majority exploring them independently (Joseph & Linley, 2008). This has posed complications when attempting to establish a narrative regarding factors which might be mutually related to both concepts (Prati & Pietrantoni, 2009), despite PTS and PTG sharing several common variables (David et al., 2021).

Literature suggests the following variables may be associated with PTS and PTG. Firstly, time elapsed since the traumatic event appears important, given the temporal course in post-traumatic reactions in parents of children with chronic physical illness (Kazak et al., 2006; Picoraro et al., 2014). Growth takes time to emerge (Tedeschi & Calhoun, 1995), with the process of re-establishing schema occurring across time (Joseph & Linley, 2005). Moreover, traumatic stress responses are normal and to be expected following an adverse event. The period of acute stress following a trauma may last up to a month following the triggering event (American Psychiatric Association [APA], 2013). Acute stress may resolve without intervention or may develop into PTS over time (Bryant et al., 2014). Conversely, greater time elapsed since diagnosis has been associated with reduced PTS in parents of children with cancer, diabetes, and injuries (Landolt et al., 2012; Le Brocque et al., 2010), and greater PTG in adults with ABIs (Collicutt-McGrath & Linley, 2006). It is clear that time may be associated with both PTS and PTG.

Secondly, coping styles are a well-established facet of both PTS and PTG (Greening & Stoppelbein, 2007; Brown et al., 2003). Greater approach-oriented coping (e.g., acceptance) has been negatively associated with PTS (Pineles et al., 2011), and positively associated with PTG (Barr, 2011). The converse has been found for avoidance-oriented

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coping styles (Turner-Sack et al., 2016; Westgate, 2019). Indeed, acceptance and commitment therapy (ACT) interventions aimed at increasing psychological flexibility (acceptance and adjustment to difficult situations; Burton & Bonanno, 2016) and reducing avoidance may mitigate distress in parents of children with ABI (Brown et al., 2015). This aligns with theories of PTS and PTG; namely, avoidance reduces post-traumatic cognitive processing (Ehlers & Clark, 2000), whilst acceptance facilitates processing and reconstruction of schema (Zoellner & Maecrker, 2006).

Furthermore, avoidant coping may reduce opportunities for seeking social support (Shipherd & Salters-Pedneault, 2008). Social support can act as a stress-buffer in PTS (Jacobsen et al., 2002). Reduced social support is a commonly cited correlate in the PTS literature, including for parents of children with paediatric illness (Kazak et al., 1997; Pinquart, 2019). Social support has also been associated with greater PTG in parents of children who have cancer (Hungerbuehler, 2011) and those who have been admitted to intensive care (Coville & Cream, 2009). Social support is complex and multifaceted, conceptualised in various ways across psychological literature leading to conflicting conclusions regarding the nature of relationship (Wang et al., 2021). Perception and quality of social support appears to be particularly important in relation to both PTG (Forinder & Norberg, 2014) and PTS (Ullman, 1999). Social support can provide opportunities to process trauma, reducing PTS (Shakespeare-Finch et al., 2015) to increase acceptance, and to reconstruct new narrative regarding the trauma, encouraging PTG (Calhoun & Tedeschi, 1995). Therefore, time since injury, avoidance-, acceptance-, and social support-coping may influence the relationship between PTS and PTG.

However, social isolation is a common experience for parents following ABI (Tyerman et al., 2017; Brown et al., 2013). More severe ABIs can increase parents' caregiving duties, restricting capacity to maintain relationships (Brown et al., 2013). This may reduce opportunities for PTG and increase risk of PTS. Severe childhood injuries elevate

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distress among parents (Kassam-Adams et al., 2009), whilst also predicting greater PTG (Hungerbuehler et al., 2011). Despite associations between injury severity, PTS, and PTG, there is currently no exploration into this relationship considering the influence of social support access.

Within this population, an improved understanding of the factors influencing the relationship between PTS and PTG could inform interventions for parents, aimed at promoting positive outcomes and ameliorating risk factors, in turn enhancing the child's rehabilitation (Kazak et al., 2006; Shand et al., 2015).

Research Hypotheses

1. There will be a positive linear (greater growth associated with greater PTS) or positive curvilinear (growth increases with PTS symptoms, but for more severe or lower levels of PTS, PTG decreases) relationship between PTS and PTG.
2. Acceptance-, social support-, and avoidance-coping will contribute to variance in PTS, whilst controlling for social network size, time since injury and injury severity.
3. Acceptance-, social support-, avoidance-coping and PTS will contribute to variance in PTG, whilst controlling for social network size, time since injury and injury severity.

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Materials and Method

Design

The quantitative study design incorporates cross-sectional and longitudinal aspects. All data was gathered cross sectionally with participants being invited to repeat outcome measures six months later. Longitudinal analyses were dependent on amount of longitudinal data collected.

Participants

Participants were parents/guardians of children aged 1-18 years. As outlined in the introduction, evidence suggests that it can take up to a month for the period of acute trauma to resolve (APA, 2013) and for PTS to potentially onset. Additionally, PTG takes time to emerge (Tedeschi & Calhoun, 1995). Therefore, only parents of children who sustained an ABI at least six months ago were eligible. d to Parents of children with a range of ABI's who were in complete or continuous remission (i.e., no longer receiving radiotherapy/chemotherapy) were eligible to participate. Parents of children with progressive neurodegenerative illness and those who are not fluent in English were excluded.

Procedure

Recruitment for this study took place online between February 2021-November 2021. Participants were recruited via non-random sampling on social media sites (Twitter, Facebook, LinkedIn), and through online advertisement by third sector organisations who support parents of children with ABI (e.g., Child Brain Injury Trust), including international organisations (e.g., Brain Injury Association of America, Brain Injured Children's Trust New Zealand). Participants were asked to share the weblink with others to establish snowball recruitment (Allen, 2017). Parents could only complete the survey online due to complications with face-to-face delivery from the Covid-19 pandemic.

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Ethics

Ethical approval for the study was granted by the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee (Ref: 2020/21-048). Institutional approval was also gained from third-sector organisations (e.g., Child Brain Injury Trust) where required. All participants gave informed consent via the online survey and data was fully anonymised. There were no gift/monetary incentives.

Measures

Demographic information (Appendix D) – Demographic information about the parent and child were collected. Parent demographics were: age, gender, ethnicity, country of residence, relationship to the child, previous experience of PTS, and whether they had received therapy/counselling for the emotional impact of their child's ABI. Details regarding the child's age, gender, ABI type, and time since injury were also collected. For those parents who reported their child suffered a traumatic brain injury (TBI), further information regarding injury severity was collected using the Mayo Classification System (Malec et al., 2007). Parents were asked to provide details on their child's presentation immediately after their child's TBI: consciousness, ability to make new memories, Glasgow Coma Score, and area of the brain worst affected.

Post-traumatic stress disorder checklist – Civilian Version (PCL-C; Weathers et al., 1993; Appendix E), is a 17-item self-report measure of PTS symptoms. It assesses symptom severity using a 5-point Likert-type scale ranging from 1 (not at all) to 5 (extremely). Scores on each item are summed to provide an overall score of PTS symptoms; higher scores indicate greater severity of PTS. Overall scores range from 17-85; scores exceeding 28 may indicate PTS. The PLC-C has good internal consistency (a=0.96) and test-retest reliability (r =0.96) (Weathers et al., 1993). The PCL-C has been used to assess PTS in parents of children experiencing other medical events such as cancer (Vernon et al., 2017).

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Post-traumatic growth inventory (PTG-I; Tedeschi & Calhoun, 1996; Appendix F), is a 21-item self-report measure of PTG. It uses a 6-point Likert-type scale ranging from 0 (I did not experience this change) to 5 (I experienced this change to a very great degree). This measure has five subscales and produces an overall score of PTG which ranges from 0-105. Total score was used for this study; higher scores indicate greater growth. This measure has good reliability (a=0.9) and acceptable test-retest reliability (r = 0.71) (Tedeschi & Calhoun, 1996).

COPE Inventory (COPE; Carver, Scheier & Weintraub, 1989; Appendix G), is a 60-item self-report measure of coping strategies. It uses a 4-point Likert-type scale, ranging from 1 (I usually don't do this at all) to 4 (I usually do this a lot). Higher scores indicate greater use of that coping strategy. This measure has 15 subscales (e.g. acceptance, denial etc), but yields no overall score. Each subscale score ranges from 4-16. Second-order factor analyses yielded the following subscales: problem-focussed, avoidant, social-support, and emotion-focussed (including acceptance) (Carver et al., 1989; Fontaine et al., 1993; Litman, 2006). For this study, social-support and avoidant-coping subscales were used alongside the original acceptance subscale as these coping strategies are associated with PTS and PTG in parents of children experiencing other medically traumatic events (Turner-Sack et al., 2016; Greening & Stoppelbein, 2007). Internal reliability for social support and avoidance are good (a= 0.71-0.85, Sica et al., 1997; a = 0.72; Ben-Zur, 2002; respectively), and acceptable for acceptance (a = 0.65; Carver et al., 1989).

Social Network Index (SNI; Cohen & Wills, 1985; Appendix H) is a 12-item self-report measure of quality and quantity of social relationships. It has three subscales: network diversity, number of people in network, and number of embedded networks. The number of people in network subscale was used. The SNI has acceptable reliability (alpha = 0.64-0.7; Platt et al., 2014).

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Life Events Checklist (LEC-5; Weathers et al., 2013; Appendix I) is a self-report measure, screening for exposure to traumatic events. It lists 16 events which may cause PTS symptoms. Item 17 accounts for any unlisted event. It does not yield a total score, rather allows for identification of trauma exposure. This measure has moderate interrater reliability (Kappa = 0.61; Gray et al., 2004). This measure was included to control for the influence of new-onset trauma between time points for analysis of longitudinal PTS and PTG data. Additionally, the LEC-5 was included to account for Covid-19 related stressors.

Data Analysis

Firstly, the data was screened for missing data. Where missing data was 10% or less, mean imputation was used (Downey & King, 1998). Where missing data exceeded 10%, the data was omitted from the analyses. Data was analysed using Microsoft Excel and IBM SPSS Statistics. Descriptive statistics were generated to characterise the sample. Prior to all analyses, potential outliers were visually and statistically examined using histograms and Z-scores (Field, 2013).

To analyse whether the relationship between PTS and PTG appeared linear or curvilinear, scatterplots were visualised. A quadratic regression sensitivity analysis was run to assess whether a curvilinear equation better fit the data compared to linear (Osborne, 2015). It was planned that if the relationship appeared more linear than curvilinear, assumptions of parametric tests (linearity, normality, and homoscedasticity) would be checked prior to running a Pearson's product-moment correlation. If a curvilinear relationship was indicated, assumptions of Pearson's product-moment correlation would be violated. Parabolic or logarithmic transformations were planned to be applied to the curvilinear data for the purposes of analyses (Allen, 2017).

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Hierarchical linear regressions were used to address research hypotheses two and three. In preparation for regression modelling, distributions of all variables were explored for normality. Where variables were non-normally distributed, transformations were applied, and sensitivity analyses conducted to explore the impact of non-normal distributions on planned regressions. Correlation matrices and variance inflation factor (VIF) scores were checked for multicollinearity between variables (Field, 2013). The assumption of homoscedasticity was checked using P-P plots (Field, 2013).

To address research hypothesis two, regression on PTS (from the PCL-C; Weathers et al., 1993) was planned entering demographics (parent age and gender), and injury severity into block one. Time since injury, social network size (from the SNI; Cohen & Wills, 1985) and number of significant life events (from the LEC-5; Weather et al., 2013) were planned to be entered into the second block to control for confounds from these variables. Finally, the predictors – acceptance-, social support-, and avoidance-coping (from the COPE; Carver et al., 1989) were planned to be entered to test for their unique contribution to variance in PTS.

For hypothesis three, regression on PTG (from the PTG-I; Tedeschi & Calhoun, 1996) was planned following the same steps for hypothesis two, with PTS (from the PCL-C; Weathers et al., 1993) as an additional predictor in the third block. If there was sufficient power, the mediating effect of acceptance-, social support, and avoidance-coping, and the moderating effect of social network size, time since injury and injury severity would be explored in the relationship between PTS and PTG using Conditional Process Modelling with the PROCESS tool (Hayes, 2017), and the Baron and Kenny (1986) approaches, respectively.

The highest number of planned predictor variables in the regression was ten. Previous studies which have found an association between PTS and PTG have reported

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medium effects (e.g., Rogan et al., 2013; Ruini et al., 2013). Based on this, a power calculation was conducted using G*Power (Erderfelder et al., 1996). Using R^2 deviation from zero, a medium effect size was inputted, using Cohen's (2013) measure of effect size for multiple regression, setting f^2 at 0.15, power at 0.8 and alpha at 0.05. A sample size estimation yielded 118 participants.

Where sample size falls short of that required for a fully powered analysis of ten variables, in attempt to reduce chance of type two error, an *a priori* plan was established to remove control variables from inferential analyses; namely, parent age as this variable was not essential in addressing the research hypotheses. Furthermore, it was planned that if insufficient participants were recruited for the longitudinal component of this study, the LEC-5 variable would not be included and all hypotheses would be addressed using a cross-sectional design.

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Results

Sample description

Seventy-seven parents responded to the survey, of whom 49 completed a sufficient proportion to be included in analyses. Thus, a total of 49 parents (46 mothers, and 3 fathers) with an average age of 49.24 years (*SD = 7.7),* completed this study. Parents were experiencing a high severity of PTS symptoms (M = 54.02, *SD* = 13.98) (Weathers et al., 1993). Seven reported to suffering from PTS prior to their child's ABI. Over 50% had received therapy and/or counselling for the emotional impact of their child's injury. Similarly, parents were experiencing high levels of PTG (M = 68.18, *SD* = 22.18) when compared to studies exploring PTG in parents of children with cancer (Irie et al., 2021; Wurz et al., 2022) and parents of children admitted to intensive care (Colville & Cream, 2009). The main characteristics of the sample can be seen in Table 1 and 2. A summary of means and standard deviations from the main outcome measures are presented in Table 3. Correlation

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analyses were completed to check for multicollinearity. No correlation statistic between variables exceeded $r < 0.8$ (Fields, 2018), therefore the assumption of no multicollinearity was met (see Table 4).

Participants who did not finish the survey to completion (N = 28) were all females. None identified as suffering from PTS prior to their child's ABI. The percentage of completion ranged from 12-59%; with most (39%) terminating the survey when answering questions regarding the injury and severity. During the recruitment phase, unsolicited feedback from participants enquiring about the study indicated this was an important and relevant topic but caregiving duties restricted their time to complete the survey.

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Table 1

Parent Demographics

Parent characteristics (N = 49)	**N (%)**
Relationship to child	
Mother	46 (94)
Father	3 (6)
Primary Caregiver	0
Ethnicity	
White	43 (88)
Asian	2 (4)
Mixed/Multiple Ethnic Groups	2 (4)
Latinx/Hispanic	1 (2)
Indigenous	1 (2)
Country of Residence	
United Kingdom	33 (67)
United States	7 (14)
Australia	3 (6)
Canada	2 (4)
Switzerland	1 (2)
Uganda	1 (2)
United Arab Emirates	1 (2)
Colombia	1 (2)
Experiencing post-traumatic stress prior to child's ABI	
Yes	7 (14)
No	42 (86)
Previously received counselling/therapy for impact of their child's ABI	
Yes	27 (55)
No	22 (45)

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Table 2

Child Demographics.

Child Characteristics (N = 49)	**N (%)**	**Mean (SD)**
Age at time of study		10.41 (5.5)
Gender		
Male	33 (67)	
Female	16 (33)	
Time since injury (months)		56.9 (49.24)
Type of injury*		
Anoxia	4 (8)	
Infection / Encephalitis	24 (48)	
Stroke/Haemorrhage/Bleed on the brain/Blood clot	10 (20)	
Tumour	3 (6)	
TBI	15 (31)	
Other	7 (14)	

Note: *parents could choose multiple injury types to describe their child's ABI.

Table 3

Mean and standard deviation of measures

Measure	**Mean**	**SD**
PTG-I Total Score	68.18	22.18
PCL-C Total Score	54.02	13.98
SNI Network Size Score	15.02	9.03
COPE Social Support Score	9.49	2.50
COPE Avoidance Score	6.66	1.32
COPE Acceptance Score	12.51	2.98

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Table 4

Correlations between variables

	1	2	3	4	5	6	7
1.PTG-I total	-						
2.PCL-C total	0.05	-					
3.Time since injury	0.12	0.06	-				
4.Acceptance coping	0.48**	-0.25	0.08	-			
5.Social Support coping	0.41**	-0.16	0.07	0.37**	-		
6.Avoidant coping	-0.06	0.5**	-0.07	-0.36*	-0.04	-	
7.Social network size (SNI)	0.29*	-0.14	0.06	0.11	0.26	-0.03	-

*Note: *p* < 0.05, ***p* <0.01

Within the data sets used for analyses (N=49), the amount of missing data for injury severity, and the small number of participants who completed the longitudinal component (N=3) meant that it was not possible to include these variables in analyses. Similarly, due to the small number of fathers who took part in this study (3), it was not considered appropriate to include gender in regression modelling. Therefore, severity of injury, parental gender, and exposure to potentially traumatic events (LEC-5) were excluded from inferential analyses. Additionally, due to the small sample, *a priori* plans were followed to maximise analytical power: age was excluded from analyses. Hypotheses were adjusted accordingly and addressed using a cross-sectional design. It was not possible to conduct mediation and moderation analyses.

Hypothesis 1: There will be a relationship between PTS and PTG

Planned inspection of scatterplots was suggestive of linear analyses. A quadratic sensitivity analysis indicated no significant additional variance was explained with the addition of the quadratic term (R^2_{change} (1, 46) = 0.00, p = 0.93), confirming appropriateness

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of linear analyses. Assumptions of parametric tests were met (Field, 2013). A Pearson product-moment correlation coefficient was computed to assess for a linear relationship between PTS and PTG. Results indicated no linear correlation between PTS and PTG (r (48) = 0.05, p = 0.73).

Hypothesis 2: Acceptance-, social support and avoidance coping will contribute to variance in PTS, whilst controlling for time since injury and social network size.

At stage one, time since injury did not significantly contribute to the regression model (p>0.05). The addition of social network size did not significantly increase variance explained by the model (p>0.05). However, with the addition of the coping variables, the regression model was significant in explaining PTS (F (5, 44) = 3.49, p=0.01), demonstrating a medium effect size and explaining approximately 20% of variance in PTS ($R^2_{adjusted}$ (3, 44) = 0.21, p<0.01). The addition of the coping variables explained significantly more variance in PTS than social network size (step two) (R^2_{change} (3, 43) = 0.26, p<0.01). In assessing the variables independently, avoidance coping was the only variable that added significantly to the regression model in the analysis of total PTS. Thus, hypothesis two was partially supported. The regression coefficients and corresponding standard errors can be seen in Table5 and the regression models can be seen in Table 6.

Table 5
Regression one coefficients and standard errors

Predictor	**B**	**SE_b**	**β**
Step 1			
Time since injury	0.02	0.04	0.06
Step 2			
Time since injury	0.02	0.04	0.06
Social network size	-0.23	0.23	-0.15
Step 3			
Time since injury	0.03	0.04	0.11

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Social network size	-0.16	0.21	-0.1
Acceptance coping	-0.16	0.7	-0.03
Social support coping	-0.61	0.8	-0.11
Avoidance coping	5.15	1.47	0.49***

Note: *p<0.05, **p<0.01, ***p<0.001

Table 6
Overall regression model one

	R^2	$R^2_{adjusted}$
Step 1	0.00	-0.02
Step 2	0.03	-0.02
Step 3	0.29	0.21**

Note: *p<0.05, **p<0.01, ***p<0.001

Hypothesis 3: Acceptance-, social support-, avoidance-coping and PTS will contribute to variance in PTG, whilst controlling for time since injury and social network size.

At stage one and two, time since injury and social network size, respectively, did not significantly contribute to the predictability of the regression models (both *p*'s >0.05). However, the overall regression model (Step 3) was significant in explaining variance in PTG scores (F (6, 43) = 4.14, p<0.01) with a large effect and explained 28% of variance. The addition of avoidance-, social support-, acceptance-coping and PTS significantly increased the proportion of variance explained by the model ($R^2_{Adjusted}$ (4, 43) = 0.28, p<0.01). The proportion of variance in PTG explained by the addition of the coping variables and PTS was significantly more when compared to step two (R^2_{change} (4, 42) = 0.28, p<0.01).

Regarding the individual variables, at stage two, social network size added significantly to the regression model in the analysis of total PTG (t(44)=1.99, p=0.05). However, at stage three, with the addition of the coping variables and PTS, social network size was no longer significant (p>0.05). Only acceptance coping significantly

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contributed to variance in PTG ($t(44) = 1.53$, $p<0.01$). Therefore, hypothesis three was partially supported with acceptance coping, but no other variable was predictive of PTG. The regression coefficients and corresponding standard errors can be seen in Table 7 and the regression model can be seen in Table 8.

Table 7
Regression two coefficients and standard errors

Predictor	**B**	**SE_b**	**β**
Step 1			
Time since injury	0.05	0.07	0.12
Step 2			
Time since injury	0.05	0.06	0.1
Social network size	0.69	0.35	0.28*
Step 3			
Time since injury	0.02	0.06	0.04
Social network size	0.52	0.31	0.21
Acceptance coping	3.14	1.06	0.42***
Social support coping	2.04	1.22	0.23
Avoidance coping	0.00	2.52	0.00
PTS	0.35	0.23	0.22

Note: *p<0.05, **p<0.01, ***p<0.001

Table 8
Overall Regression model two

	R^2	$R^2_{adjusted}$
Step 1	0.01	-0.01
Step 2	0.09	0.05
Step 3	0.37	0.28**

Note: *p<0.05, **p<0.01, ***p<0.001

Discussion

This study explored the relationship between PTS and PTG in parents of children with ABI. Results suggest PTS and PTG are not linearly or curvilinearly related. Collectively,

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acceptance-, avoidance- and social support-coping were significant in explaining PTS, but only avoidance coping made a unique contribution, partially supporting hypothesis two. Partial support was also found for hypothesis three: the overall regression model was significantly predictive of PTG. However, only acceptance-coping contributed significantly to unique variance in PTG, whilst avoidance-, social support-coping and PTS did not.

There is a lack of consensus regarding the relationship between PTS and PTG (Prati & Piertrantoni, 2009). Curvilinear relationships have been reported in parents of children who were briefly admitted to intensive care (<12 hours) (Colville & Cream, 2009), suggesting moderate levels of PTS are associated with PTG (Picoraro et al., 2014). In the current study, many parents (>70%) scored within the 'severe' range for PTS. Extreme distress may inhibit PTG (Tedeschi & Calhoun, 2004). Additionally, the relationship may be multidimensional: certain PTG domains may relate to certain PTS domains (Shakespeare-Finch & Armstrong, 2010). However, this study only explored overall scores of PTG and PTS.

A recent meta-analysis exploring correlates of PTS and PTG found the relationship between PTS and PTG diminished in samples whose trauma resulted from ill-health (Shand et al., 2015). Similarly, paediatric medical models of PTS and PTG posit trauma responses may be contextually different. Threat is often future-oriented and there is less opportunity to reach the 'post-trauma' position due to ongoing treatment (Kazak et al., 2006; Picoraro et al., 2014). Qualitative studies exploring the emotional impact of paediatric ABI on parents report perpetual grief and fear about the future (Jordan & Linden, 2013). Therefore, in this sample, parents may be re-traumatised as their child progresses through treatment and rehabilitation, with elevated levels of PTS impacting a possible relationship with PTG. This may contrast to single-event, time-limited trauma where the individual can learn the triggering event is no longer threatening (e.g., brief admissions to intensive care; Colville & Cream, 2009). A longitudinal design accounting for treatment variables (e.g., post-acute

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treatment) may better conceptualise the potential relationship between PTS and PTG across time, if one exists. Nevertheless, PTS and PTG were unrelated in parents of children with other chronic illnesses (Chardon et al., 2021; Irie et al., 2021). For parents of children with ABI, PTS and PTG may be independent (Joseph & Linley, 2008).

This study also explored the relationship between avoidance-, social support- and acceptance- coping and PTS. Whilst the overall model was significant, only avoidance-coping had a positive and significant contribution to PTS variance. This aligns with cognitive models of PTS, which suggest avoidance hinders trauma processing, manifesting as symptoms characteristic of PTSD (Ehlers & Clark, 2000). Avoidance is positively associated with PTS in parents of children with brain tumours (Westgate et al., 2019), and cancer (Norberg et al., 2011). However, avoidance is also a symptom of PTS and thus conceptual overlap may explain these results. Additionally, coping styles only explained 20% of variance in PTS, suggesting other factors unaccounted for may contribute to PTS. These might include treatment duration/intensity (Pinquart, 2019), resilience (Sharp et al., 2021) and rumination (Perez et al., 2018).

Social support did not significantly contribute to variance in PTS. This poses questions regarding the contextualisation of relationship between social support and PTS. In parents of children experiencing other medical events, negative relationships between social support and PTS have been documented (Brown et al., 2003). However, social isolation is a common experience among ABI survivors (Salas et al., 2021) and their parents/carers (Tyerman et al., 2017). Aligning with existing research, there was a negative relationship between social network size and social support-coping with PTS, but this was non-significant. This may be attributable to the small effect sizes documented between social support and PTS (Wang et al., 2021) and the limited statistical power of this study to detect such effects. An alternative hypothesis concerns the usefulness of social networks in supporting individuals to process trauma-related information (Ullman, 1999), which may

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moderate the relationship between social support coping and trauma outcomes – a factor which was not accounted for by the current study. Moreover, the protective influence of social support against PTS may vary across populations (Brewin et al., 2000). As this is the first study exploring psychosocial factors in relation to PTS in parents of children with ABI, it is difficult to draw robust conclusions regarding the relationship between PTS and social support. These conclusions are further complicated by the number of parents who reported pre-existing PTS.

Contrasting to previous research, acceptance-coping was not significantly associated with PTS. Previous studies report a negative relationship with approach-based coping (e.g., acceptance) and PTS (e.g., Pineles et al., 2011). This may be attributable to perceived controllability of the trauma, which was not measured in this study. Approach-based coping may be more effective when stressors are perceived as controllable (Scrapa et al., 2006).

The final aim of this study was to determine the extent to which acceptance-, social support, avoidance-coping and PTS relate to PTG in parents of children with ABI. PTG levels were comparable to parents of children with other medical conditions (Turner-Sack et al., 2016; Byra et al., 2021). In support of hypothesis three, acceptance-coping was positively associated with PTG, conforming with theories of PTG that suggest accepting situations which cannot be changed, such as some consequences of ABI, is crucial for PTG (Zoellner & Maercker, 2006). However, there is a dearth of studies exploring acceptance in PTG, perhaps owing to difficulties in measuring the concept. Given the results of the current study, and previous research finding a positive association between acceptance and psychological outcomes in parents of children with TBI (Wade et al., 2001), exploration of acceptance coping in relation to PTG warrants further research.

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Social support did not contribute to unique variance in PTG. This is a surprising result given the wealth of literature evidencing this relationship (Tedeschi & Calhoun, 2004; Kinsella et al., 2015). In a meta-analysis exploring factors which contribute to PTG, social support, and social support-coping were found to have medium effect sizes (Prati & Peitrantoni, 2009). This study may have been underpowered to detect such effects.

These results may also be attributable to measures used to assess social support. Social support is multifaceted; evidence regarding what types of social support facilitate PTG is mixed (Simon et al., 2019). For example, the COPE (Carver et al., 1989) has been used in similar studies to assess social support-coping in relation to PTG (e.g., Turner-Sack et al., 2016). However, this study also failed to find a significant relationship between the two, despite the social support subscale having good reliability (a = 0.71-0.85, Sica et al., 1997). The social support subscale of the COPE is comprised of both instrumental social support (problem-focussed, seeking assistance, and information), and emotional social support (emotion-focussed, moral support, sympathy and understanding) (Litman, 2006). Models of PTG (e.g., Tedeschi & Calhoun, 1994) suggest empathetic and understanding social support can facilitate PTG, helping craft narratives regarding posttraumatic change (Zoellner & Maecrker, 2006). This type of social support is likely to align with the emotional social support subscale of the COPE which was not explicitly assessed in this study.

Furthermore, perceived social support (i.e., awareness of someone who could offer social support) seems to be more important for positive psychological change rather than the support itself (Wu et al., 2021). Previous studies which report a relationship between social support and PTG used measures designed to assess parents' perception of social support (e.g., Hungerbuehler et al., 2011). Perhaps, the measure in this study did not capture perceived social support, explaining the non-significant relationship. Moreover, the SNI used to assess social network size asks questions regarding workplace relationships. These relationships may not reflect the confiding relationship parents of

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children with ABI require to process trauma. Alternative, theoretical explanations include when social support is offered. Social support immediately following a trauma is predictive of later PTG, providing opportunities to process trauma-related information (Schroevers et al., 2010). Alternative measures such as the Multidimensional Scale of Perceived Social Support (MSPSS; Wilcox, 2010) may better capture the relationship between social support and PTG.

Limitations and Future Research

A primary limitation of this study is the small sample. A priori and post-hoc calculations indicate some statistical methods used in this study were underpowered for detecting medium and small effects. However, adequate power was achieved for detecting large effects. Further, due to difficulties with recruitment and power, it was not possible to include all variables identified *a priori*. If a sufficiently large sample had been recruited to power the *a priori* analyses, background variables including parent gender and age would have been included in both regressions at step one to control for confounds from these variables. Sufficient longitudinal data would have contributed to a better understanding of how the relationship between PTS and PTG might change over time, within the limitations of an observational study. A larger sample size may have also allowed sufficient power to explore the mediating effect of acceptance-, social support- and avoidant-coping, as well as the moderating effect of social network size, time since injury and injury severity in the relationship between PTS and PTG (regression two). This may have allowed exploration of potential mechanisms in the relationship between PTS and PTG.

Most participants were female, thus results of this study largely reflect mothers' experiences. Additionally, child brain injury type was primarily encephalitis or TBI, with most parents residing in the UK and some in the USA and Australia. Because of the small sample size this may reduce internal validity, increasing risk of error variance due to heterogeneity

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across the sample and pose complications for detecting weaker effects. Concepts such as PTG, PTS and social support may vary across cultures (Spelvins et al., 2010; Brannan et al., 2013; Hinton & Lewis-Fernandez, 2011), which is unlikely to be reflected in the results. Future research should aim to recruit from a more diverse demographic.

Twenty-nine parents did not complete the survey and thus their results were excluded from analysis. Many terminated the survey when answering questions regarding their child's injury. These questions may have been particularly upsetting for parents, and perhaps those who did not complete the survey may have different psychological outcomes (e.g., greater avoidance). Similarly, unsolicited feedback highlighted time taken to complete the survey was an issue. Future studies should make greater use of patient and public involvement (PPI) to address recruitment challenges relating to emotiveness of material and time required.

Further limitations of this study include cross-sectional design. Evidence from the literature suggests PTS and PTG can vary across time (Shakespeare-Finch & Lurie-Beck, 2013; Weber, 2014) which could not be explored by the current research. Moreover, on average, five years had passed since ABI onset in the current sample. Other stressful events and concurrent illness may have occurred which were not accounted for in this study. This study also took place during the Covid-19 pandemic which may have influenced posttraumatic responses, availability of social support, resourcefulness to use adaptive coping, and subsequent outcomes of this research. Future research should employ longitudinal designs to allow tracking of the evolution of PTS and PTG over time.

Finally, self-reports of PTG (e.g., PTG-I) have been criticised as to whether they reflect actual positive changes, or a positive recall bias which is protective against distressing life events (Frazier et al., 2009). Some critics question the validity of the PTG construct, suggesting it reflects coping rather than a trauma outcome (McMillen & Cook,

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2003). The validity of PTG measures could be improved using prospective studies to compare differences between pre- and post-trauma indicators of growth (Fraizer et al., 2009), and via multiple PTG measures (Linley & Joseph, 2004).

Clinical Implications

Whilst the results from this study are tentative and should be interpreted cautiously, findings indicate that parents of children with ABI can experience both PTS and PTG and the two may be independent. Parents' PTS can impair their ability to implement medical treatment for their child (Anderson et al., 2005); professionals should consider adopting trauma-informed care for this population. Parents may also benefit from psychological intervention. Cognitive-behavioural therapy (CBT) is recommended for PTS (NICE, 2018), which is based on cognitive theories of PTS that suggests avoidance may maintain symptoms (Ehlers & Clark, 2000). CBT techniques such as cognitive restructuring and exposure may reduce avoidance and modify problematic event-related appraisals, encouraging helpful contextualisation of trauma information (Bryant et al., 2003). As avoidance-coping contributed to variance in PTS, such treatments may be beneficial for parents of children with ABI. Reductions in avoidance could also promote flexible cognitive processing and meaning making, encouraging PTG (Wagner et al., 2016).

As previously discussed, there has been a call for clinical psychology to broaden the lens through which it perceives human phenomenology (Linley & Joseph, 2004). A more dimensional model might focus on health and fulfilment, as much as illness and distress (Joseph & Linley, 2008). PTS and PTG were independent in the current study, although they may not be mutually exclusive (Linley & Joseph, 2004). Coping was significantly associated with both PTS and PTG, supporting research suggesting they share common variables (David et el., 2021). Interventions aimed at increasing acceptance-coping and reducing avoidance-coping (e.g., ACT) may decrease PTS and foster PTG in this

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population (West, 2013). ACT-informed interventions for parents of children with ABI aimed at increasing psychological flexibility and reducing experiential avoidance mitigated distress for parents (Brown et al., 2015). Brown and colleagues (2015) did not assess PTG as an outcome explicitly, yet evidence from the current study suggests such interventions might enhance PTG via acceptance. PTG may enhance psychological wellbeing and life satisfaction (Kinsella et al., 2015), which may consequently improve outcomes for the child (Taylor et al., 2001; Anderson et al., 2005).

Conclusions

This study aimed to explore the relationship between PTS and PTG and related psychosocial factors in parents of children with ABI. PTS and PTG were not found to be related. Coping was significant in explaining some variance in both PTS and PTG; with avoidance-coping contributing to unique variance in PTS, and acceptance-coping contributing to unique variance in PTG. Alternative variables which were not included in this study may explain further variance. Although the results of this study are constrained by methodological and power limitations, interventions targeting avoidance- and acceptance-coping may alleviate distress and promote positive psychological wellbeing in parents. Further longitudinal research examining posttraumatic responses in parents of children with ABI is warranted. A more diverse sample of participants including dads would be beneficial. Analysis of dimensions of PTS, PTG and coping is needed to determine specific relationships given possible conceptual overlap between coping, PTS and PTG.

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Chapter Five: Additional Methodology

This chapter contains supplementary methodology detail to the methods included in the empirical paper.

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Extended Methodology: Empirical Study

1. Research Hypotheses

Due to issues arising from missing data and inability to complete the longitudinal component of this study, it was not possible to include a number of variables in inferential analyses. These included injury severity, parent gender, and occurrence of other potentially traumatic events. Secondly, due to issues with recruitment, and a priori plan to remove control variables was followed to reduce risk of type two error. Namely, parent age was not included in inferential analyses as it was not essential in addressing the research hypotheses. Further details can be found in the design section of this chapter. A priori research hypotheses were adjusted to align with the removal of variables.

The a priori hypotheses were as follows:

1. There will be a linear or curvilinear relationship between posttraumatic stress (PTS) and posttraumatic growth (PTG).
2. Acceptance-, social support- and avoidance-coping will contribute to variance in PTS, whilst controlling for parent age, social network size, time since injury, injury severity and significant life events.
3. Acceptance-, social support-, and avoidance-coping will contribute to variance in PTG, whilst controlling for parent age, social network size, time since injury, injury severity and significant life events.

The amended hypotheses were:

1. There will be a linear or curvilinear relationship between posttraumatic stress (PTS) and posttraumatic growth (PTG).
2. Acceptance-, social support-, and avoidance-coping will contribute to variance in PTS, whilst controlling for social network size and time since injury.

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3. Acceptance-, social support-, avoidance-coping and PTS will contribute to variance in PTG, whilst controlling for social network size and time since injury.

Furthermore, a priori plans indicated a possibility for the exploration of mediation and moderation analyses between variables in the relationship between PTS and PTG, leading to the following hypotheses:

4. Acceptance-, social support-, and avoidance-coping will mediate the relationship between PTS and PTG.

5. Social network size, time since injury and injury severity will moderate the relationship between PTS and PTG.

6. Increased social support-coping and reduced avoidance-coping will increase engagement in acceptance coping. This was hypothesised to reduce PTS and increase PTG.

7. Injury severity will reduce social network size. This will increase PTS and reduce PTG.

8. Reduced social networks will diminish opportunities for social-support and acceptance-coping. This will increase PTS and reduce PTG.

Following an internal review of the empirical study proposal by staff working in the department of Clinical Psychology at the University of East Anglia, it was established that the first three hypotheses detailed in the main empirical study paper were sufficient to satisfy requirements for the Clinical Psychology Doctorate. Therefore, priori plans were to conduct these analyses in an exploratory manner if the statistical test achieved sufficient power. This power was not achieved and thus these hypotheses were not explored.

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2. **Design.**

There were two possible designs for this study: cross-sectional and longitudinal. The second data collection (Time 2 (T2)), required for longitudinal design, was planned to increase validity of conclusions (Taris & Kompier, 2014). However, the completion of this component of the study was contingent on a pre-determined number of participants completing the Time 1 (T1) survey before May 2021 (see procedure). Given this potential challenge, it was pre-determined that all hypotheses could be addressed using a cross-sectional design.

3. **Participants**

In August 2021, recruitment for this study was extended to Spanish speaking participants. This was following an approach from a collaborator (Professor Alfonso Caracuel) based at the University of Granada. This opened recruitment to a broader range of participants including those based in Spain and Latin America (see procedure for further information).

4. **Measures**

For the Spanish component of this study, all measures and participant-facing information were translated to Spanish by collaborators. Back-translation was also completed to ensure accuracy of translated versions.

5. **Procedure.**

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Detailed Procedure. Following ethical approval, recruitment for this study was completed via two processes: (1) 'snowballing' on professional social media pages (e.g., Facebook and Twitter), and (2) via third-sector organisations who work with parents of children with acquired brain injuries (ABI).

Due to anticipated difficulties with recruiting from a niche sample, preliminary contact was made with some third-sector organisations to explore potential interest in supporting this research. Once ethical approval was gained, this was shared with third-sector organisations alongside the participant information sheet (PIS) (Appendix J) and the study protocol. Additionally, some organisations (Child Brain Injury Trust, UK; Encephalitis Society, UK) required completion of an internal approval process. The following organisations facilitated recruitment for this project:

- Child Brain Injury Trust, UK
- Encephalitis Society, UK
- The Children's Trust, UK
- Meningitis Now, UK
- RECOLO, UK
- Brain Injury Association of America, USA
- Centre of Brain Injury Research & Training, USA
- Brain Injured Children, New Zealand

Third-sector organisations advertised this study via word of mouth, sharing the web-link to the study on their social media pages, and via their newsletters and websites. Participants were required to click on a web-link to gain access to the survey (operated by Qualtrics). The survey was only accessible online due to complications from face-to-face data collection caused by the Covid-19 pandemic.

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Participants were firstly presented with the PIS (Appendix J), followed by a consent form (Appendix K). Once participants consented to participate, they were presented with the questionnaires in the following order: demographic questionnaire, Posttraumatic Stress Disorder Checklist (PCL-C), Posttraumatic Growth Inventory (PTG-I), the COPE inventory (COPE), Social Network Index (SNI) and the Life Events Checklist (LEC-5). These questionnaires were piloted on two individuals providing patient and public involvement (PPI) for the project and to gather information on the practicalities of measure administration. The questionnaire took approximately 30 minutes to complete in total. Upon completion of the survey, participants were asked if they would like to participate in T2 data collection (note: information regarding T2 data collection was also detailed in the PIS). Those who wished to participate were asked to enter their email address so they could be contacted at a later date and were assigned a random unique identifier by Qualtrics. Participants were then presented with an aftercare sheet (Appendix L), regardless of whether they entered an email to participate in T2. The aftercare sheet was also downloadable from Qualtrics as indicated on the PIS.

Longitudinal Component. Those participants who consented to participate in T2 data collection were automatically emailed by Qualtrics six-months after completing the T1 survey. The random unique identifier assigned to participants at T1 was automatically carried over by Qualtrics for the purposes of matching data sets across time points. Participants were again presented with a PIS (Appendix M) and were required to give renewed consent to participate in T2 data collection. Participants were then presented with the following questionnaires: PTG-I and LEC-5. Completion instructions for the LEC-5 asked participants to refer to events which had occurred since T1. After completion, participants were presented with the aftercare sheet (Appendix L) which was downloadable from Qualtrics.

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A priori calculations were conducted to ascertain how many participants would be required to achieve sufficient power in data analyses within the allocated time schedule of the Doctoral Thesis for Clinical Psychology. This indicated that 92 participants would be required by May 2021 to achieve sufficient power for the longitudinal analysis of this study. The primary researcher monitored participant uptake, with plans to extend recruitment if meeting this appeared unlikely. Despite involvement of additional third-sector organisations in recruitment, only three participants completed the T2 data collection and therefore the longitudinal component of this study was not completed. Research hypotheses were addressed using a cross-sectional design.

Spanish-speaking Component. The Spanish-speaking component of this study is ongoing. The primary supervisor will pursue this in collaboration with Professor Alfonso Caracuel. The procedure for recruitment and participation for the Spanish-speaking component of this study is the same as that for the English-speaking component. Spanish-speaking participants will be recruited via circulation of the weblink on professional social media platforms (e.g. Facebook and Twitter).

6. Ethics:

Approval. Ethical approval for the study was granted by the University of East Anglia (UEA) Faculty of Medicine and Health Sciences Research Ethics Committee (Reference: 2020/21-048; Version 6; Appendix N). Amendments were submitted relating to additional recruitment organisations and the inclusion of the Spanish language version of the study which were also approved.

Consent. Participants were provided with PIS's that were developed using guidance from the Health Research Authority (HRA, 2017) (Appendix J & M). Separate participant information sheets were made for the T1 and T2 components of the study. The PIS detailed

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required information to make an informed decision about participation. The PIS for T1 informed participants about the option to sign up to T2 at the end of the survey. After the PIS, participants were presented with the consent form (Appendix K). Participants were required to click to the following page of the survey if they consented to participate. The consent form reminded participants that they could withdraw at any point before submitting their answers but that they could not withdraw after this due to the anonymised data set. In keeping with the British Psychological Society (BPS, 2014) code of human research ethics, participants were able to download a copy of the consent form from Qualtrics. Participants were required to give renewed consent at T2.

Coercion. Chance of coercion was reduced in this study as participants only clicked on the weblink to participate if they desired. Further, no incentives were used for participation.

Confidentiality. All data from this survey was fully anonymised. Data storage and handling on Qualtrics is compliant with GDPR. The data was downloaded from Qualtrics to the primary researchers UEA OneDrive. All email addresses were immediately deleted from the data set. The resulting data was shared with the research team via UEA OneDrive – an encrypted network drive which allows secure data sharing and is supported by the UEA.

Participants did not provide any personally identifiable information unless they opted to participate in T2, in which case they provided an email address. However, participants were automatically emailed by Qualtrics, and email addresses were stored securely on Qualtrics for the duration of data collection. Email addresses associated with participant responses were immediately deleted before analysis. The UEA Research Data Management Policy (UEA, 2019) will be adhered to; the data will be archived for at least six years after publication. Following this, the data will be destroyed.

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Distress. It is possible that the content of the surveys may have been distressing for participants. However, following a pilot trial with PPI, parents of children with ABI did not report any undue distress. Furthermore, the survey covered both potentially distressing symptoms as well as positive experiences gained through traumatic events. Participants were also provided with an aftercare sheet which detailed support services in the UK, Spain, and globally (Appendix L). Regardless of participants' country of residence, further information on childhood ABIs could be accessed through the websites detailed on the aftercare sheet. Participants were advised to follow their normal route of accessing general healthcare if they were concerned about theirs or their family's wellbeing. The aftercare sheet was automatically presented to participants following completion of the surveys. Those who withdrew were able to download the aftercare sheet from Qualtrics, as detailed in the participant information sheets.

7. Patient and Public Involvement:

Due to the Covid-19 pandemic, PPI involvement was restricted during the planning stage. Nevertheless, two parents of children with ABI inputted on the patient-facing material at the request of the researcher and asked to provide feedback on information presentation and comprehensibility of the content for this population. Plans for the empirical project were presented to a workgroup of four parents of children with ABI at the Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR) who felt the project aligned with their personal experiences of adjustment following their child's ABI. One parent highlighted the need to approach the concept of PTG tentatively with parents who are navigating a highly challenging and complex world following their child's injury, emphasising that some may struggle to identify benefits immediately following the injury. This issue was addressed as participants only clicked on the link to participate if they consented to do so. Moreover,

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participants were informed they could terminate the survey at any point by closing their browser.

There are further plans to involve PPI in dissemination of the research results: involving parents of children with ABI in presenting the research outcomes in an accessible way. The results of this study will be shared with those third-sector organisations who supported recruitment.

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Chapter Six: Additional Results

This chapter contains results that are supplementary to the analyses included in the empirical paper.

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Additional Results: Empirical Study

Missing data

Data was downloaded from Qualtrics to an Excel spreadsheet on the University of East Anglia (UEA) OneDrive. Each measure was manually scored by one researcher (AP). Approximately 30% of the complete data set were incomplete. Percentage of completion for those participants ranged from 12-93%. When using regression analyses, two possible strategies might be used to address incomplete data: (1) mean imputation and (2) weighted imputation (Columbia University School of Public Health, 2019). Due to the number of incomplete data sets exceeding 30% (with a general rule of thumb suggesting imputation should not be used where more than 5% of overall data is missing; Tabachnick & Fidell, 2007), and variable completion rates, it was decided that mean imputation or weighted imputation for all incomplete data sets would substantially increase bias in results, particularly due to the small sample size (Jakobsen et al., 2017). However, due to limitations with the sample size and subsequent impacts on power, guided by Downey and King (1988), it was decided that mean imputation would be used for those data sets where less than 10% of data was missing. This method has been shown to have good representation of the original data (Downey & King, 1988). Data sets where more than 10% of data were missing were dropped from analyses.

Regressions

Multiple regression was used to address research hypotheses two and three. The way in which predictors are entered into a model can impact outcomes (Field, 2013). There are multiple methods of entering variables into a linear model, such as hierarchical, forced and stepwise (Horber, 2021). As recommended by Field (2013), in this study, variables were entered into the regression in a hierarchical manner based on theoretical background. This method of entering variables is considered superior as it provides statistical control and ability to examine incremental validity compared to stepwise entry which is vulnerable to sampling variation (Field, 2013; Lewis, 2007).

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Adjusted R^2 statistics were reported in the model summary for both regressions, as they provide a more accurate explanation of variance whilst accounting for the number of predictors in the model (Leach & Henson, 2007). The model also illustrated the unique contribution of each predictor to the model, which were reported as beta weights (β) in tables 4 and 6. The use of Beta weights helps to conceptualise the unique strength of a relationship between the independent and dependent variables in standardised units (Field, 2013).

Power

Guidance on power for regression is variable across the literature, with power reducing with the addition of variables (Clark-Carter, 2010). One rule of thumb suggests that sample sizes for regression should be N > 50 + 8m (where N is the total sample size, and m is the number of predictors) (Green, 1991). On the other hand, 15 participants per variable have been suggested to be adequate (Clark-Carter, 2010). Regressions were planned with a maximum of 10 predictors (i.e., a priori hypothesis two). A priori power calculations for this regression were conducted using G*Power (Erdfelder et al., 1996). Previous research indicates a medium effect size between posttraumatic stress (PTS) and posttraumatic growth (PTG) (Rogan et al., 2013), thus, a medium effect size was inputted utilising Cohen's (2013) measure of effect size for multiple regression, setting f^2 at 0.15. Outputs yielded an estimated sample of 118 participants would be required to achieve sufficient power ($1 - \beta = 0.8$; Field, 2013). Underpowered regression analyses can increase risk of type two error (Maxwell, 2004). It was not possible to include parent age, severity of injury and potential exposure to other traumatic events in analyses due to missing data an inability to complete the longitudinal component of this study. To address issues with power whilst retaining ability to test the theoretically driven model as outlined in the a priori plan, parent age was not included in inferential analyses.

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Subsequently, the maximum number of variables used in the regression models was six (hypothesis two). A power calculation was conducted in G*Power (Erdefeleder et al., 1996). Cohen's (2013) effect size for regression was used, setting f^2 at 0.15, a medium effect. This yielded an estimated sample size of 77 participants. This suggests the analyses in this study may be underpowered as the sample consisted of 49 participants. Whilst underpowered analyses are common across psychological literature, Maxwell (2004) suggests some of the problems arising from this can be mitigated by providing reports of effect size. Post-hoc power calculations of both regression models indicated the sample size was sufficient to detect large effect sizes ($f^2 > 0.4$; Cohen, 2013), yielding an estimated power of >90% for both models. However, power estimates dropped to approximately 45% and 9% for medium and small effects, respectively, suggesting these models may not have had sufficient power to detect medium or small effects.

Additionally, post-hoc sample size calculations indicated that, for the first overall regression model with five predictors, setting the achieved effect size of f^2 at 0.4, and alpha at 0.05, and estimated power of 0.91, the sample size estimate yielded 49 participants. For the second overall regression model with a total of six predictors, setting the achieved effect size of f^2 at 0.58, alpha at 0.05, and the estimated power of 0.9, the sample size estimate yielded 50 participants. The sample size achieved in this study was adequate for the detection of large effect sizes.

Statistical Analysis Assumptions

Correlation was used to address hypothesis one, and regressions were conducted to address research hypotheses two and three. Each statistical analysis and corresponding test assumptions are detailed below.

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Correlation. Prior to correlational analyses, each variable, PTS and PTG, were analysed for normality using scatterplots and Z-scores (Field, 2013). Both PTS and PTG met the assumption for normality.

Next, both variables were visually examined for outliers using histograms and scatterplots (Field, 2013). For the PTG (measured by the posttraumatic growth inventory; PTG-I) and PTS (measured by the posttraumatic stress checklist; PCL-C) variables, visual inspection indicated the possibility of outliers. Z-scores were therefore calculated in SPSS to establish if outliers were statistically problematic (Field, 2013). Field (2013) suggests that 5% or less of the distribution should have Z-scores >1.96, 1% or less should have Z-scores >2.58, and very few should score above 3.29, with approximately 95% of cases falling within the normal range. Output for the Z-scores of the PTG-I and the PCL-C indicated <2% had Z-scores exceeding 1.96 and therefore represented normal variation.

Finally, scatterplots were visualised to ascertain the linearity of the relationship. Field (2013) advises linear analyses can proceed if the data does not appear explicitly non-linear. Thus, a Pearson's product-moment correlation was conducted to test the linearity of this relationship, yielding insignificant results. A curvilinear relationship was also explored due to the growing literature base evidencing this relationship between PTS and PTG (e.g. Weber, 2014; Shakespeare-Finch & Laurie-Beck, 2014; Colville & Cream, 2009). This was completed using the quadratic regression method. A hierarchical regression was used to first test the presence of the linear term, then adding a second step using the quadratic term of the independent variable and regressing it on to the dependent variable. This allows comparison of variance explained between the linear and quadratic relationship (Osborne, 2015; Field, 2013) and has been used in similar studies (Weber, 2013; Kleim & Ehlers, 2009). The regression output (R^2 change) indicated that the addition of the quadratic term

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did not explain any further variance andthus the relationship was also not assumed to be curvilinear.

Regression. For both regressions, each variable was visually inspected for normality using scatterplots and histograms. Guided by Field (2013), normality for skew and kurtosis were tested by calculating z-scores using the kurtosis/skew statistic and its standard error. Where these Z-scores > 1.96, the data is significantly skewed and/or kurtotic. All variables were normally distributed except for the social network index score (SNI) and acceptance coping. The SNI variable indicated positive skew and kurtosis, thus, as guided by Field (2013), logarithmic transformations were applied. For the acceptance coping variable, the Z-score for the skew statistic indicated a negative skew, thus, guided by Field (2013), a reverse score transformation was applied. Sensitivity analyses were conducted to explore the impact of non-normal distribution on the planned regression models. Transformation of the variables had minimal impact on subsequent regression output, thus, analyses proceeded with the untransformed variables.

Outliers for each variable were visually examined through histograms and scatterplots (Field, 2013). Other than those outliers identified for the PTG-I (PTG) and PCL-C (PTS) variables, as detailed in the above section, no further outliers in any other variables were identified.

Assumptions of linearity and homoscedasticity was checked by analysing P-P plots and the scatterplots of the standardised residuals (*ZRESID) against the standardised predicted values of the outcome variable (*ZPRED). For both regressions, residuals were equally distributed and there appeared to be no systematic relationship between the error in the model and what the model predicts, therefore meeting the assumption of linearity and homoscedasticity (Field, 2013).

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Predictor variables for both regressions were also assessed for multicollinearity using the correlation matrix. For both regressions, no predictor variables had a correlation coefficient exceeding 0.8, and therefore the assumption of no multicollinearity was met (Field, 2013).

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Chapter Seven: Discussion and Critical Evaluation

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Discussion and Critical Evaluation

The overarching aim of this thesis was to explore trauma and growth responses in parents of children with chronic illness and acquired brain injuries (ABI). Over recent years, there has been a growing agenda in clinical psychology practice and theory to expand upon the medical model which seeks to eliminate abnormality and pathology, to a more inclusive and holistic approach, exploring what makes life for all people valuable, productive, and fulfilling despite inevitable human suffering (Joseph & Linley, 2008; Hayes & Hoffman, 2017). This aligns with the more recent development of third-wave therapies which apply across the dimension of psychopathology to flourishing (Hayes & Hofmann, 2017). This is particularly important for individuals and families living with chronic physical illnesses, where elimination of pathology is not always possible (Graham et al., 2016).

One positive psychological concept which has been growing in the literature of chronic physical illness is posttraumatic growth (PTG): positive psychological development following the struggle with trauma. This may be, in part, attributable to the wealth of literature suggesting chronic physical illness can trigger posttraumatic stress (PTS) (Martz & Cook, 2001; Pinquart, 2019). Parents who care for a child suffering with a chronic physical illness may be particularly susceptible to such responses, as diagnosis and caring for an unwell child is considered one of the most emotionally challenging experiences (Carmassi et al., 2018). Nevertheless, it is also important to recognise that such experiences may lead to PTG for parents (Picoraro et al., 2014). To facilitate this dimensional approach of ill-health and flourishing in practice (Weich et al., 2011), a better understanding of the factors associated with PTG for parents of children with chronic physical illness is necessary. This thesis aimed to address aforementioned gaps in the literature; namely, exploring what factors correlate with PTG in parents of children with chronic physical illness specifically, and to explore the relationship between PTS and PTG in parents of children with ABI.

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To the author's knowledge, this thesis makes a unique contribution to the literature as it explores what factors correlate with PTG explicitly in parents of children with chronic physical illness. This extends upon previous reviews which explored correlates in broader paediatric samples, including parents of children with neurodevelopmental disorders, acute, and functional illnesses (e.g., Kritikos et al., 2021; Picoraro et al., 2014). Data from 29 papers were subject to systematic review and narrative synthesis. Many studies were conducted on parents of children with cancer and were fair quality; the impact of bias was considered throughout the synthesis. Overall, results suggest that PTG is likely to increase across time for parents of children with chronic physical illness. There was also tentative evidence for specific cognitive processing factors, which, aligning with models of PTG (Tedeschi & Calhoun, 2004), may be interrelated. For example, more severe illness perception may cause greater disruption to core beliefs, increasing parental experience of PTS. Whilst most included studies failed to find a relationship between PTS and PTG, one study suggested a curvilinear relationship with moderate levels of PTS contributing to PTG. Deliberate rumination was also associated with greater PTG, perhaps, as a mechanism of rebuilding schema following disruption. Increased levels of anxiety were associated with PTG, which may arise when parents accept and acknowledge the changes which accompany chronic physical illness. Coping strategies such as positive religious coping and good quality social support were also associated, possibly buffering these negative psychological outcomes and providing a framework to re-construct adaptive core beliefs regarding the illness. There was evidence to suggest the process of PTG in parents of children with chronic physical illness may be facilitated through psychological interventions which target cognitive reappraisal and promote deliberate rumination through mindfulness practice, but future research is needed to explore how benefits from intervention might be maintained across time. Further, longitudinal studies measuring the evolving process of PTG across time and in a broader sample including fathers and more diverse chronic physical conditions, such as those with neurological conditions, could increase generalisability of conclusions.

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The findings of the systematic review largely aligned with previous reviews (Kritikos et al., 2021; Picoraro et al., 2014). However, some important differences emerged. Firstly, both prior reviews identified an association between PTS and PTG. Kritikos et al. (2021) reports a positive association between the two constructs, but also identifies a possibility of a curvilinear relationship. This is somewhat different to the current study, where most papers failed to find a significant relationship between the two and one study reported a curvilinear relationship. For parents of children with chronic physical illness, PTS and PTG may co-exist and be unrelated. As suggested by the paediatric medical traumatic stress model (Kazak et al., 2006), parents may be retraumatised by subsequent medical treatment experiences. Concurrently, parents need to establish ways to adaptively cope, perhaps through ascribing positive meaning. Thus, PTS and PTG may be experienced simultaneously for parents of children with chronic physical illness. Secondly, subjective illness severity/perception was identified as a correlate of PTG in Picoraro et al. (2014), but not by Kritikos et al. (2021). This is an important distinction between the two reviews given the inclusion of a diverse range of paediatric conditions such as neurodevelopmental conditions and functional disorders by Kritikos et al., (2014). Illness perception may be less relevant in such conditions, given that neurodevelopmental disorders are present from birth. The process of perceiving and adjusting to diagnosis may differ to the onset of a chronic illness after a period of normal development (e.g., cancer, or indeed, ABI). Similarly, the treatment demands of functional disorders may be less intensive than those of chronic conditions, influencing subsequent illness perceptions and potential for PTG. Overall, time, good quality social support, religiosity and cognitive processes including core belief disruption, deliberate rumination and illness perception are likely to be important processes for PTG across diverse paediatric conditions. For parents of children with chronic physical illness specifically, PTS may not be a pre-requisite for PTG. Parents' subjective appraisal of illness severity may influence subsequent cognitive processing associated with PTG.

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An empirical study followed from the systematic review aiming to explore the relationship between PTS and PTG in parents of children aged 1-18 years with an ABI, a chronic condition that causes significant disruption to the child and parents' lives. Analyses were also conducted to explore the influence of avoidance-, acceptance-, and social support-coping on PTS and PTG, independently. A cross-sectional design was used; 49 parents' data was analysed using regression. Overall, PTS and PTG were not linearly or curvilinearly related in this sample. The overall regression for PTS was significant, but only avoidance coping contributed significantly to variance in PTS. Similarly, the overall regression for PTG was significant, but only acceptance coping made a unique contribution to PTG. Therefore, PTS and PTG may coexist but be unrelated in this population, although both may be influenced by coping styles. Tentative suggestions were made regarding the usefulness of interventions which aim to reduce avoidance and facilitate acceptance (e.g. acceptance and commitment therapy, ACT; cognitive-behavioural therapy, CBT) to increase PTG and reduce PTS. However, the robustness of these conclusions is limited by the cross-sectional design: there may be overlaps in the constructs of PTS and avoidance, and PTG and acceptance. Cross-sectional design allows identification of shared variance, rather than identification of relationships between independent variables. Sample size prevented ability to analyse sub-components of these constructs or detection of smaller effects, limiting the extent to which the study was able to test hypotheses regarding more complex mechanisms.

Suggestions for future research include the exploration of further factors such as illness perception and different aspects of social support (e.g. perception of social support). A more detailed analysis of the mediative and moderative relationships between variables may be of benefit: for example, level of injury severity may influence parents' caregiving duties (Brown et al., 2013), restricting their capacity to build and maintain relationships, reducing engagement with social support coping. Avoidance-coping may reduce opportunities for acceptance and seeking social support, which are known to be protective against PTS (Holeva et al., 2001) and predictive of PTG (Brown et al., 2003). Furthermore,

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as previously discussed, the relationship between PTS and PTG may be multidimensional (Shakespeare-Finch & Armstrong, 2010) with specific domains of PTG being related to PTS (Morris et al., 2005). Such explorations were beyond the remit of the current study. Longitudinal, and qualitative research could improve understanding of posttraumatic responses in this population.

Strengths and Limitations

The systematic review offered a comprehensive synthesis of existing quantitative research. It explored the correlates of PTG in parents of children with chronic physical illness explicitly, further clarifying and extending upon previous research exploring correlates of PTG in other paediatric samples (Kritikos et al., 2021; Picoraro et al., 2014). Given that PTG can improve psychological adaptation (Helgeson et al., 2006) and parent wellbeing is predictive of child outcomes (Corsi et al., 2021), a better understanding of what factors are associated with PTG in this population might enable amelioration of risk factors and facilitation of PTG.

A particular strength of this review relates to its methodological rigour in selection of studies. For example, the research team carefully deliberated the definition of “chronic physical illness”, a term which has considerable variation across healthcare practice, literature, and policy (Bernell & Howard, 2016). The definition used was derived by classifications of two sources. Firstly, the definition from the National Institute of Health (NIH, n.d.). This definition has been used in similar reviews published by Cochrane (Law et al., 2019). Secondly, Medical Subject Headings (MeSH) were used, which are based on biomedical concepts (Baumann, 2016). Collectively, it was felt this definition was inclusive enough to capture all chronic physical illnesses. Where there was ambiguity regarding whether certain medical conditions aligned with the definition, a decision was made in collaboration among the researchers based on clinical knowledge and experience. This is a particular strength of this review relative to similar others, which failed to report how chronic conditions were operationalised (e.g. Kritikos et al., 2021; Picoraro et al., 2015).

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Secondly, this review included any study reporting quantitative results in association with PTG, including the use of randomised controlled trials (RCTs) which provided more robust evidence for causation and clinical application. Studies of all methodological quality were eligible for review to increase reliability(Higgins et al., 2011). However, synthesis was stratified by methodological rigour of included studies to reduce possible source of bias in results and subsequent conclusions (Popay et al., 2006; Higgins et al., 2011). Risk of bias in observational studies was assessed using the NIH quality assessment tools (NIH, 2014), and RCTs were assessed using the risk-of-bias tool (RoB2; Sterne et al., 2019) which are suggested to be the most effective and reliable assessment tools for their corresponding study designs at present (Ma et al., 2020). In addition, 40% of extracted data was checked for reliability by a second reviewer (PW); uncertainties were resolved through a third reviewer (FG). All papers were subject to quality review by two reviewers (AP and PW); agreement rate was acceptable, achieving 80% (Belur et al., 2018).

Overall, the methodological rigour of the narrative review was strong. This enabled robust conclusions to be drawn regarding the correlates of PTG in parents of children with chronic physical illnesses, within the constraints of the methodological limitations of the included studies. However, one notable limitation to the analytical approach was the lack of meta-analysis due to the heterogeneity in measures of independent variables. This also posed complications during the synthesis process and when drawing conclusions. For example, social support was found to be positively associated with PTG. However, the relationship is complicated due to the complexity of the construct of social support and the different ways it was conceptualised, including perception and quality of social support, and attendance at social support groups such as mental health services.

Another limitation of this study was the interchangeable use of post-traumatic growth and benefit finding in the systematic searches. PTG refers to the process of positive psychological change in interpersonal relationships, self-perception, and life perspective in struggling with a trauma (Tedeschi & Calhoun, 1996), whilst benefit finding is defined as the

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process of assigning beneficial value to a traumatic event (Helgeson et al., 2006). Some suggest that benefit finding may occur immediately following a trauma, whilst PTG is more progressive across time (Mols et al., 2009). Furthermore, these two concepts have been associated with different predictive factors (Sears et al., 2003). Thus, to increase specificity of conclusions, future research might benefit from comparing correlates for benefit finding and PTG individually. Nonetheless, the literature base alludes to overlap between the concepts with similar reviews exploring PTG using both terms in searches (Yastibas & Karaman, 2021; Ng et al., 2021; Marziliano et al., 2020); and broader interchangeability between the terms (e.g. Helgeson et al., 2006; Shakespeare-Finch & Laurie-Beck, 2014; Joseph & Linely, 2008; Mols et al., 2009). Furthermore, as the exploration of PTG in this sample is niche and the limited number of studies available, the research team made the decision to include both terms.

The empirical study of this thesis was, to the author's knowledge, the first of its kind to explore post-traumatic reactions in parents of children with ABI. The study identifies the importance of focus on both PTS and PTG in this population and the possible implications this may have in facilitating parental wellbeing. The planning and design of the study was clinically informed: clinical psychologists working in the field of paediatric ABI, and parents of children with ABI contributed to the research design and planning. Furthermore, collaborators at the University of Granada facilitated the translation of study materials into Spanish, recognising the clinical need for this research. The involvement of multiple third-sector organisations globally potentially increased the generalisability of these results. Variables included in the regression models of this study were carefully selected following a scoping review of the literature by the primary author and through discussion with the wider research team. The results of this study outline the need for a more nuanced conceptualisation of the specific components of relationship between domains of PTS and PTG.

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However, the empirical study had numerous limitations. Firstly, the small sample size. Although attempts were made by the research team to maximise recruitment (e.g., involvement of global ABI organisations, involvement of PPI), this study recruited fewer participants than anticipated, and a significant number of participants began the survey but did not finish it to completion. Of note, this survey took approximately 30 minutes to complete. Additional to routine child-care, caring for a child with an ABI is time-consuming (Brown et al., 2013). Indeed, one parent reported that they were unable to complete the survey due to their caregiving responsibilities. It is therefore plausible to consider that the length of this survey may have impacted recruitment. Another possible explanation may be due to the nature of survey content; namely, asking parents to reflect on the trauma of their child's ABI. Consistent with theories of trauma (Ehlers & Clark, 2000), more traumatised parents may be more avoidant of taking part in such research leading to underrepresentation of these parents in this study. This is particularly pertinent, given the results of the systematic review suggest that perception of illness (with greater severity of illness being associated with increased trauma) may be related to traumatic responses in parents of children with chronic physical illness.

A further limitation of the sample in this study was the small number of fathers (N = 3) who took part compared to mothers (N = 46). This is particularly important, given that the results of the systematic review suggesting the possibility of gender differences in PTG for parents of children with chronic physical illness. This reflects broader difficulties across psychological research which suggests fathers are more difficult to recruit and less likely to participate than mothers (Phares, 1995). This means that the posttraumatic reactions of fathers of children with ABI was minimally reflected in the results of this empirical study. Although mothers and fathers were both eligible and encouraged to participate in this study, one suggested way father participation might be encouraged is through direct solicitation of media that may capture their interest and emphasise the importance of their participation (Parent et al., 2017).

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Moreover, some variables were removed from analyses. No variables in either regression model violated the assumption of multicollinearity ($r > 0.8$) (Field, 2013), therefore, the research team decided to remove variables based on rate of data completion. Missing data for injury severity, lack of father participants, and inability to complete the longitudinal component of this study meant parental gender, exposure to potentially traumatic events, and injury severity were excluded from analyses. Although all variables were chosen based on a scoping review of the literature, some variables (e.g., parent age), were not pertinent in addressing the research hypotheses and therefore were removed from analyses to increase statistical power. Whilst this may reduce the methodical credibility of this research, a balanced decision was required regarding the ethical importance of analysing collected data and contributing to the research base with minimal bias.

Although some variance was accounted for by the regression models, a proportion was not, indicating that variables which were not accounted for in the study may play an important role in predicting PTS and PTG. Indeed, factors such as illness perception, core belief disruption and deliberate rumination, which were not accounted for in the models, may be associated with PTG in parents of children with chronic physical illness, as suggested by the results of the systematic review of this thesis. These factors have also been associated with PTS (David et al., 2021). However, due to the research structure of the Clinical Psychology Doctorate, the planning phase for the empirical study took place prior to the systematic review. Furthermore, time constraints, hypothesised difficulties with recruitment, and subsequent power meant it was not possible to include all variables for modelling. Future studies should seek to explore the role of these cognitive factors in association with PTS and PTG in parents of children with ABI.

Finally, it must be acknowledged that this empirical study took place during the Covid-19 pandemic which may have influenced outcomes. For example, the study aimed to explore the use of social support, which, for many, was significantly reduced throughout the pandemic. Additionally, the negative psychological impacts of Covid-19 have been

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documented (Gloster et al., 2020; Xiong et al., 2020; Pfefferbuam et al., 2020), with some experiencing it as a trauma (Bridgland et al., 2021; Sun et al., 2021). Although attempts were made to account for the influence of trauma caused by the pandemic by including the Life Events Checklist (LEC-5), this variable was dropped due to power limitations and inability to complete the longitudinal component of the study. It is therefore not possible to evaluate the influence of Covid-19 on results and conclusions. The outcomes of the empirical study must be considered in context.

Clinical Implications

Historically, psychological interventions have been implemented within a medical system (Byrne et al., 2019). This approach has been criticised for its narrow lens in which psychological suffering is perceived and treated: specifically, the alleviation of symptoms and deficits (Maddux & Lopez, 2015). There has been a call for a more inclusive approach to psychological wellbeing, operating dimensionally across ill health, flourishing and fulfilment (Joseph & Linely, 2008; Department of Health, n.d.). Whilst the medical model has limitations, psychological approaches operating within this system have the potential to alleviate psychological suffering. Arguably, and aligning with the results of this thesis, alleviation of distress and avoidance in PTS may facilitate approach-based coping which is necessary for PTG. Whilst this is important, there is also scope for psychological approaches to build upon meaning making and to support positive outcomes resulting from trauma.

This is of clinical relevance as parents of children with chronic physical illnesses and ABI often receive treatment in acute hospital environments which may have a greater tendency to focus on pathology instead of positive experiences and growth (Hallam, 2012). The results of this thesis suggest parents of children with chronic physical illness may experience PTS and PTG simultaneously; thus, it may be beneficial for clinicians working with this population to broaden their perspective of posttraumatic responses not only leading to distress but also as a precursor to growth. Although, by its nature of originating from traumatic events, PTG has been associated with negative affect such as anxiety (Riva et al.,

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2014), it is also predictive of lower PTS across time (Linley et al., 2008), and has been associated with positive psychological outcomes such as improved quality of life and wellbeing (Sim et al., 2015; Morrill et al., 2008). Although the relationship between PTS and PTG might be complicated and variable, the results of this thesis suggest services should consider the possibility of both outcomes regardless of the nature or extent of relationship between them.

PTG may also be facilitated through psychosocial interventions (Calhoun & Tedeschi, 2004; Tedeschi & Calhoun, 2004; Roepke, 2015; Li et al., 2021). Emphasis is placed on taking a person-centred approach, supporting, and encouraging positive changes that are described by the client, simultaneously acknowledging the dialectic process of distress as well as benefits derived from a trauma (Calhoun & Tedeschi, 1995). Mindfulness and cognitive-behavioural therapy (CBT) stress management may be effective in facilitating PTG (Li et al., 2021), as they can enable helpful rumination in a structured way whilst reappraising negative or unhelpful meanings. Synthesising the outcomes of this thesis, it would be plausible to consider that interventions which aim to reduce avoidance, encourage acceptance and cognitive processing through deliberate rumination may be of particular benefit for parents of children with chronic physical illness. Possible psychological approaches which encompass these components include CBT and ACT, encouraging acceptance and reducing avoidance. ACT also draws upon mindfulness-based practice, which may support the individual to deliberately ruminate in a structured way, enabling the process of core belief reconstruction (Garland et al., 2015). Moreover, there is emerging evidence for the use of ACT in the treatment of PTS (Pohar & Argaez, 2017). Therefore, ACT-informed interventions may be of particular benefit to this sample in ameliorating PTS and encouraging PTG, which could serve to improve psychological outcomes for these parents and subsequently for their child.

Given the results of the systematic review suggest social support can increase PTG, the efficacy of ACT/CBT interventions for this population may be facilitated through co-

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delivery with mentors with lived experience (Tulip et al., 2020) or delivery within a group context with similar others (e.g., Rosenberg et al., 2019; Brown et al., 2014). Furthermore, more naturalistic interventions aimed at increasing opportunities for social support may be of benefit for this sample, particularly for parents of children with ABI who report social isolation (Tyerman et al., 2017). Within naturally occurring, safe social contexts, individuals might find the right types of support to enable new meaning and growth. Indeed, in samples of ABI, attendance at community groups with similar others was found to increase self-acceptance and purpose (Berger et al., 2020) and facilitate PTG (Lyon et al., 2021).

However, there is debate about whether attempts should be made to target PTG, or indeed, whether individuals need help with PTG as for many this occurs spontaneously (Joseph & Linley, 2008). Interventions aimed at facilitating PTG might undermine this natural experience (Joseph & Linley, 2008). For some, this might inflict harm when exposed to the assumption that they can or should experience benefit from the trauma (Wortman, 2004). Furthermore, the understanding of PTG, and indeed, the relationship between PTS and PTG is complex and perhaps we do not yet know enough about this phenomenon to correctly facilitate development with interventions (Joseph & Linley, 2008), particularly for parents of children with ABI where there is a significant dearth of research.

Theoretical Implications

As previously discussed, the results of this thesis align with existing theories of PTS (e.g., Ehlers & Clark, 2000) and PTG (Tedeschi & Calhoun, 1998; David et al., 2021). However, there is debate in the literature about the extent to which PTG reflects veridical positive change (Wortman, 2004). For example, some suggest that PTG is a defensive illusion when so much is lost following a trauma – depicting oneself in a more positive view to convey they are coping well (Wortman, 2004). Others suggest PTG may just be evidence of an individual coping well with trauma (McMillen &–Cook, 2007). Moreover, much of the literature on PTG is limited by its cross-sectional design which relies on participants retrospectively recalling the experience of growth (Fraizer et al., 2009; Wu et al., 2019;

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Martin et al., 2017). This poses complications due to accuracy of recall of the process of change over a period of time and thus perception of growth as documented by self-reports may not reflect actual change (Joseph, 2015). In this thesis, PTG was predominantly assessed in cross-sectional designs using self-report measures of PTG. It has been suggested that to adequately assess if change has occurred, PTG should be tracked over time (Wortman, 2004). Therefore, it cannot be concluded with certainty that the conclusions from this thesis accurately represent PTG.

Additional to this, the process of PTG may be better conceptualised using qualitative methods. Indeed, PTG theorists suggest that PTG should be understood from a humanistic perspective, specifically that individuals and their phenomenology are unique (Joseph, 2018). Measures such as the posttraumatic growth inventory (PTG-I) have been criticised for their lack of application across different demographic samples, such as health populations, having been developed on a student sample (Joseph & Linley, 2008). Thus, its applicability of conceptualising growth in samples of parents of children with chronic physical illness and ABI may be limited and hinder conceptualisation of the unique growth experience of this population. The use of qualitative measures may highlight any nuance in this process which is unique to parents of children with chronic physical illness. This is of particular importance in samples where PTG has not been previously explored, such as parents of children with ABI.

Integrative theories of wellbeing may be appropriate for this population. For example, the PERMA model (Seligman, 2011) incorporates hedonism (that is, subjective experience of positive emotions, reductions in negative emotions, and life satisfaction; Lucas & Deiner, 2008) and eudemonism (such as psychological wellbeing theory which emphasises components of wellbeing such as meaning, purpose, self-acceptance, personal growth, autonomy and positive relationships; Ryff, 1996). Collectively, the PERMA model suggests wellbeing is comprised of components which are not mutually exclusive: positive emotions, engagement, relationships, meaning and accomplishments (Seligman, 2011). The results of

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this thesis suggest that parents can experience positive psychological outcomes such as PTG, but also negative psychological outcomes such as PTS and anxiety. PTS was associated with avoidance-coping, and PTG is likely to be facilitated by deliberate rumination and acceptance. Arguably, these processes would rely on approach-oriented coping, and the reduction of avoidance. Thus, an integrated model targeting both concepts may be beneficial for wellbeing in this population. Indeed, the facilitation of positive emotion and the alleviation of distress can broaden thought processes and associated behavioural responses, leading to more flexible thinking and action (Fredrickson, 2001). .

Finally, there is theoretical debate about the usefulness of PTG as a concept given the mixed results in the literature regarding its association with both positive and negative psychological outcomes (Zoellner & Maercker, 2006). PTG theorists suggest indices of growth that include, but are not limited to, wisdom, altered perspective on life, improved relationships and compassion are simply not controversial and are psychologically adaptive in their own right (Joesph, 2019). From a humanistic perspective, the validity of PTG of a construct should not be questioned based upon association with indicators of mental health or illness (i.e., absence of symptoms) which are predominant in the illness paradigm (Joseph, 2019).

Conclusions

Onset of a paediatric chronic physical illness or ABI is a highly emotive experience for parents and may be experienced as traumatic. Improving the health and wellbeing of these parents is a priority as parents assume key roles in the care and rehabilitative process for these children. Holistic and humanistic approaches to psychological theory and practice have been growing, exploring psychological wellbeing beyond alleviation of psychopathology to valued living and flourishing. Within the context of trauma, PTS and PTG can be considered two important aspects of human phenomenology following trauma. This thesis portfolio contributed to current research by exploring the correlates of posttraumatic growth in parents of children with chronic physical illness. It also investigated the relationship

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between PTS, PTG and coping strategies in parents of children with ABI. Findings suggest that social support, and approach-based mechanisms such as acceptance-coping, deliberate rumination, may contribute to the process of PTG.

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Appendices

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Appendix A - International Journal of Applied Positive Psychology Author Guidelines

Instructions for Authors

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” on the right and upload all of your manuscript files following the instructions given on the screen.

Please ensure you provide all relevant editable source files. Failing to submit these source files might cause unnecessary delays in the review and production process.

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Article types

- Research paper – average length approximately 7,500 words including references. Articles should be no shorter than 5,000 words and no longer that 10,000 words.
- Review article – average length approximately 10,000-12,500 words including references.
- Brief reports of null findings, replications, sensitivity testing or method variance – This format focuses on publishing null findings, replications, or analyses testing the effects of applying different methods or samples (sensitivity testing and method effects). Note the latter can be re-analyses of previously published papers. Typical length maximum 500 words introduction, 500 word discussion, 2500 word method and results sections (not including tables and figures). No supplementary materials sections.

Title Page

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

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If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration, followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

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Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX. We recommend using Springer Nature's LaTeX template.

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

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Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the

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first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm0000185
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435
- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.

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- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.
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Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

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Appendix B – Systematic Review Full Electronic Search Strategy

Medline (Ovid)

Concept	Parents	Children	Post-traumatic growth
Free text	**(**Carer* or mother* or mum* or maternal* or father* or dad* or paternal* or guardian* or care giver* or caregiver or parent*).ti.ab.	**(**((young or school) ADJ (people* or person* or adult* or child* or age*)) or youth* or juvenile* or child* or pediatric* or paediatric* or teen* or infan* or baby* or toddler or neonate* or adolescen*).ti,ab	(post-traumatic growth or posttraumatic growth or positive growth or benefit finding or stress related growth or stress-related growth or positive change or PTG or positive adaptation or thriving or adversarial growth).ti.ab.
Controlled vocab terms	exp Parents	Child ; Disabled Children ; Child, Preschool ; Adolescent	Posttraumatic Growth, Psychological; Psychology, Positive; Optimism; Emotional Adjustment

Embase (Ovid)

Concept	Parents	Children	Post-traumatic growth
Free text	(Carer* or mother* or mum* or maternal* or father* or dad* or paternal* or guardian* or care giver* or caregiver or parent*).ti.ab.	(((young or school) ADJ (people* or person* or adult* or child* or age*)) or youth* or juvenile* or child* or pediatric* or paediatric* or teen* or infan* or baby* or toddler or neonate* or adolescen*).ti,ab	(post-traumatic growth or posttraumatic growth or positive growth or benefit finding or stress related growth or stress-related growth or positive change or PTG or positive adaptation or thriving or adversarial growth).ti.ab.

`

Controlled vocab terms	exp Parents	adolescent, child, "child, Preschool"	Psychology, Positive

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Psychinfo

Concept	Parents	Children	Post-traumatic growth
Free text	("Carer*" or "mother*" or "mum*" or "maternal*" or "father*" or "dad*" or "paternal*" or "guardian*" or "care giver*" or "caregiver*" or "parent*") .ti.ab.	(((“young” or “school”) N (“people*” or “person*” or “adult*” or “child*” or “age*”)) or “youth*” or “juvenile*” or “child*” or “pediatric*” or “paediatric*” or “teen*” or “infan*” or “baby*” or “toddler” or “neonate*” or “adolescen*”).ti,ab	(“post-traumatic growth” or “posttraumatic growth” or “positive growth” or “benefit finding” or “stress related growth” or “stress-related growth” or “positive change” or “PTG” or “positive adaptation” or “thriving” or “adversarial growth”).ti.ab.
Controlled vocab terms	DE "Parents" OR DE "Adoptive Parents" OR DE "Expectant Parents" OR DE "Fathers" OR DE "Foster Parents" OR DE "Homosexual Parents" OR DE "Mothers" OR DE "Parental Characteristics" OR DE "Single Parents" OR DE "Stepparents" OR	DE "Pediatrics" OR DE "Lennox Gastaut Syndrome" = 28138; DE DE "Child Health" OR DE "Adolescent Health" OR DE "Early Adolescence"	DE "Posttraumatic Growth"

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	DE "Surrogate Parents (Humans)"

CINAHL

Concept	Parents	Children	Post-traumatic growth
Free text	("Carer*" or "mother*" or "mum*" or "maternal*" or "father*" or "dad*" or "paternal*" or "guardian*" or "care giver*" or "caregiver*" or "parent*") .ti.ab.	(((“young” or “school”) N (“people*” or “person*” or “adult*” or “child*” or “age*”)) or “youth*” or “juvenile*” or “child*” or “pediatric*” or “paediatric*” or “teen*” or “infan*” or “baby*” or “toddler” or “neonate*” or “adolescen*”).ti,ab	("post-traumatic growth" or "posttraumatic growth" or "positive growth" or "benefit finding" or "stress related growth" or "stress-related growth" or "positive change" or "PTG" or "positive adaptation" or "thriving" or "adversarial growth").ti.ab.
Controlled vocab terms	MH ("parents+")	(MH "Child+"); (MH "Adolescence+")	(MH "Posttraumatic Growth")

PILOTS

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Concept	Parents	Children	Post-traumatic growth
Free text	ti("Carer*" or "mother*" or "mum*" or "maternal*" or "father*" or "dad*" or "paternal*" or "guardian*" or "care giver*" or "caregiver*" or "parent*") OR ab("Carer*" or "mother*" or "mum*" or "maternal*" or "father*" or "dad*" or "paternal*" or "guardian*" or "care giver*" or "caregiver*" or "parent*")	ti((((“young” or “school”) NEAR/0 (“people*” or “person*” or “adult*” or “child*” or “age*”)) or “youth*” or “juvenile*” or “child*” or “pediatric*” or “paediatric*” or “teen*” or “infan*” or “baby*” or “toddler” or “neonate*” or “adolescen*”)) OR ab((((“young” or “school”) NEAR/0 (“people*” or “person*” or “adult*” or “child*” or “age*”)) or “youth*” or “juvenile*” or “child*” or “pediatric*” or “paediatric*” or “teen*” or “infan*” or “baby*” or “toddler” or “neonate*” or “adolescen*”))	ti(("post-traumatic growth" or "posttraumatic growth" or "positive growth" or "benefit finding" or "stress related growth" or "stress-related growth" or "positive change" or "PTG" or "positive adaptation" or "thriving" or "adversarial growth")) OR ab(("post-traumatic growth" or "posttraumatic growth" or "positive growth" or "benefit finding" or "stress related growth" or "stress-related growth" or "positive change" or "PTG" or "positive adaptation" or "thriving" or "adversarial growth"))
Controlled vocab terms	MAINSUBJECT. EXACT.EXPLODE(“parents”)	MAINSUBJECT. EXACT.EXPLODE("Children"); MAINSUBJECT. EXACT.EXPLODE ("Adolescents")	MAINSUBJECT. EXACT.EXPLODE ("Positive Effects")

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Web of Science

Concept	Parents	Children	Post-traumatic growth

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Free text	TI=("Carer*" or "mother*" or "mum*" or "maternal*" or "father*" or "dad*" or "paternal*" or "guardian*" or "caregiver*" or "caregiver*" or "parent*"); AB=("Carer*" or "mother*" or "mum*" or "maternal*" or "father*" or "dad*" or "paternal*" or "guardian*" or "caregiver*" or "caregiver*" or "parent*")	TI=((((“young” or “school”) NEAR/0 (“people*” or “person*” or “adult*” or “child*” or “age*”)) or “youth*” or “juvenile*” or “child*” or “pediatric*” or “paediatric*” or “teen*” or “infan*” or “baby*” or “toddler” or “neonate*” or “adolescen*”))	TI=(("post-traumatic growth" or "posttraumatic growth" or "positive growth" or "benefit finding" or "stress related growth" or "stress-related growth" or "positive change" or "PTG" or "positive adaptation" or "thriving" or "adversarial growth")) OR ab=(("post-traumatic growth" or "posttraumatic growth" or "positive growth" or "benefit finding" or "stress related growth" or "stress-related growth" or "positive change" or "PTG" or "positive adaptation" or "thriving" or "adversarial growth"))

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OR
AB=((((“young”
or
“school”)
NEAR/0
(“people*” or
“person*” or “adult*”
or “child*” or “age*”)
)
or
“youth*”
or
“juvenile*”
or
“child*”
or
“pediatric*”
or
“paediatric*”
or
“teen*”
or
“infan*”
or
“baby*”
or
“toddler”
or
“neonate*”

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	or “adolescen*”))

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Appendix C – Systematic Review Outcome of Quality Appraisals

Supplementary table: Quality appraisal of Observational studies

Observational studies	Barakat et al. (2020)				Behzadi et al. (2018)				Bender (2010)				Czyzowska et al. (2021)				Dirik & Ayas (2018)				Gardner et al., (2017)				Hong et al., (2019)			
	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	N	NA	NR	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR
Was the research question clearly stated?	×				×				X								×				×				x			
Was the study population clearly defined?	×				×				X								×				×				x			
Was the participation rate of eligible persons at least 50%?	x							X		X					×	×				×				×				X
Were all the subjects selected or recruited from similar populations? Were inclusion/ exclusion criteria prespecified and applied uniformly to all participants?	×				×				X											×	×				X			
Was a sample size justification, power description, or variance and effect estimates provided?	X					X			X				×			×		×				×			X			
For the analyses, were the exposure(s) measured prior to outcome(s) being measured?	×				×				X								×				×				X			
Was the timeframe sufficient to see an association between exposure and outcome if it existed?	X					X				X			×					×				×				X		
For exposures that can vary in levels, did the study examine different levels of the exposure as related to the outcome?	x				×				x								×				×				x			

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Were the independent variables clearly defined, valid, reliable, and implemented consistently across all participants?	X						x		X				×				×				×				X					
Was the exposure(s) assessed more than once over time?	X					X				X			×				×				×				X					
Were the dependent variables clearly defined, valid, reliable, and implemented consistently across participants?	×				×				X								×				×				x					
Were the outcome assessors blinded to exposure status of participants?			X				X				X				×				×				×				X			
Was loss to follow-up after baseline ≤20%?		X					X				x				×				×				×				X			
Were confounding variables measured and adjusted statistically for impact on the relationship between exposure(s) and outcome(s)?	X						X		X				×				×				×				X					
	Good				Poor				Fair				Fair				Poor				Fair				Fair					

Supplementary table continued: Quality appraisal of Observational studies

Observational studies	Hullmann (2013)				Hullmann et al. (2014)				Kim (2015)				Kim (2017)				Michel et al. (2010)				Nakayama et al. (2016)				Oginska-Bulik & Ciechomska (2016)			
	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR
Was the research question clearly stated?	×				×				×				×				X				X				X			
Was the study population clearly defined?	×				×				×				×				X				X				X			
Was the participation rate of eligible persons at least 50%?	×				×							×	×				X				X				X			

`

Were all the subjects selected or recruited from similar populations? Were inclusion/ exclusion criteria prespecified and applied uniformly to all participants?	×			×			×			×			x			x			X		
Was a sample size justification, power description, or variance and effect estimates provided?		×			×			×			×			X			X			X	
For the analyses, were the exposure(s) measured prior to outcome(s) being measured?	×			×				×			×			X			X			X	
Was the timeframe sufficient to see an association between exposure and outcome if it existed?		×			×			×			×			X			X			X	
For exposures that can vary in levels, did the study examine different levels of the exposure as related to the outcome?	×			×			×				×			X			X			x	
Were the independent variables clearly defined, valid, reliable, and implemented consistently across all participants?	×			×			×			×				X			x			X	
Was the exposure(s) assessed more than once over time?		×			×			×			×			X			x			X	
Were the dependent variables clearly defined, valid, reliable, and implemented consistently across participants?	×			×			×			×				X			X			X	
Were the outcome assessors blinded to exposure status of participants?			×			×			×			×			x			x			X	

`

Was loss to follow-up after baseline ≤20%?			×				×				×						×				X				X			
Were confounding variables measured and adjusted statistically for impact on the relationship between exposure(s) and outcome(s)?	×				×				×				×				x				X				X			
	Fair				Fair				Fair				Poor				Fair				Fair				Fair			

Supplementary table continued: Quality appraisal of Observational studies

Observational studies	Turner-Sack (2007)				Turner-Sack et al. (2015)				Weber (2014)				Cadell et al. (2014)				Chardon et al. (2021)				Hungerbuehler et al. (2011)				Irie et al. (2021)				Riva et al. (2014)			
	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR
Was the research question clearly stated?	×				×				×				×				X				X				X				x			
Was the study population clearly defined?	×				×				×				×				X				X				X				X			
Was the participation rate of eligible persons at least 50%?		X				X			X				×							X	X					X			X			
Were all the subjects selected or recruited from similar populations? Were inclusion/ exclusion criteria prespecified and applied uniformly to all participants?	×				×				×				×				X				X				X				X			
Was a sample size justification, power description, or variance and effect estimates provided?		×				×				X			X				X					X			X					X		

`

For the analyses, were the exposure(s) measured prior to outcome(s) being measured?	×	×	×	×	X	X	X	X
Was the timeframe sufficient to see an association between exposure and outcome if it existed?	×	×	X	×	X	X	X	X
For exposures that can vary in levels, did the study examine different levels of the exposure as related to the outcome?	×	×	×	X	X	X	X	x
Were the independent variables clearly defined, valid, reliable, and implemented consistently across all participants?	×	×	×	×	X	x	X	X
Was the exposure(s) assessed more than once over time?	×	×	X	×	X	x	X	X
Were the dependent variables clearly defined, valid, reliable, and implemented consistently across participants?	×	×	×	×	X	X	X	X
Were the outcome assessors blinded to	X	x	x	×	x	x	X	X

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exposure status of participants?																				
Was loss to follow-up after baseline ≤20%?				X			X			X		×		X			X		X	
Were confounding variables measured and adjusted statistically for impact on the relationship between exposure(s) and outcome(s)?		X					X	×			X		X		x		X		x	
	Poor				Poor			Good			Fair		Fair		Fair		Fair		Good	

Supplementary table continued: Quality appraisal of Observational studies

Observational studies	Burke & Hooper (2017)				Byra et al., (2021)				O-Hanlon et al., (2012)			
	Y	N	NA	NR	Y	N	NA	NR	Y	N	NA	NR
Was the research question clearly stated?	×				×				×			
Was the study population clearly defined?	×				×				×			
Was the participation rate of eligible persons at least 50%?	x							X		x		
Were all the subjects selected or recruited from similar populations? Were inclusion/ exclusion criteria prespecified and applied uniformly to all participants?	×							x	×			
Was a sample size justification,		×						x		X		

`

power description, or variance and effect estimates provided?												
For the analyses, were the exposure(s) measured prior to outcome(s) being measured?	×			×			X					
Was the timeframe sufficient to see an association between exposure and outcome if it existed?		×			×			X				
For exposures that can vary in levels, did the study examine different levels of the exposure as related to the outcome?	×			×			×					
Were the independent variables clearly defined, valid, reliable, and implemented consistently across all participants?	×				X		×					
Was the exposure(s) assessed more than once over time?		×			×			X				
Were the dependent variables clearly defined, valid, reliable, and implemented consistently across participants?	×			×			×					

`

Were the outcome assessors blinded to exposure status of participants?		X			X		x	
Was loss to follow-up after baseline ≤20%?		X		X			X	
Were confounding variables measured and adjusted statistically for impact on the relationship between exposure(s) and outcome(s)?	x		x		×			
	Good		Fair		Poor			

`

Supplementary table continued: Quality appraisal of Randomised Controlled Trials

Randomised Controlled Trials	Choi & Kim (2018)					Rosenberg et al. (2019)					Rosenberg et al. (2021)					Lindwall et al. (2014)				
Question	Y	PY	PN	N	NI	Y	PY	PN	N	NI	Y	PY	PN	N	NI	Y	PY	PN	N	NI
Domain 1: Risk of bias arising from the randomisation process																				
1.1 Was the allocation sequence random?					x	x						x							x	
1.2 Was the allocation sequence concealed until participants were enrolled and assigned to interventions?					x		x				x						x			
1.3 Did baseline differences between intervention groups suggest a problem with the randomisation process?				X					x					x					x	
Risk of bias judgement:	*Some Concerns*					*Low Risk*					*Low Risk*					*Some Concerns*				
Domain 2: Risk of bias due to deviations from the intended interventions (effect of assignment to intervention)																				
2.1 Were participants aware of their assigned intervention during the trial?		x				x					x					x				
2.2. Were carers and people delivering the interventions aware of participants' assigned intervention during the trial?			x			x					x					x				
2.3 If Y/PY/NI to 2.1 or 2.2 were there deviations from the intended intervention that arose because of the trial context?									x				x					x		
2.4 If Y/PY to 2.3: Were these deviations likely to have affected the outcome?																				
2.5 If Y/PY/NI to 2.4: Were these deviations from intended intervention balanced between groups?					x															
2.6 Was an appropriate analysis used to estimate		x				x					x									x

`

the effect of assignment to intervention?								
2.7 If N/PN/NI to 2.6: was there a potential for a substantial impact (on the result) of the failure to analyse participants in the group to which they were randomised?							x	
Risk-of-bias judgement:	*High Risk*		*Low Risk*		*Low Risk*		*Some Concerns*	
Domain 3: Risk of bias due to missing outcome data								
3.1 Were data for this outcome available for all, or nearly all, participants randomised?		X		x		x		x
3.2 If N/PN/NI to 3.1: is there evidence that the result was not biased by missing outcome data?		X	x		x			x
3.3 If N/PN to 3.2: Could missingness in the outcome depend on its true value?	x						x	
3.4 If Y/PY/NI to 3.3: Is it likely that missingness in the outcome depended on its true value?	x						x	
Risk-of-bias judgement:	*High Risk*		*Low Risk*		*Low Risk*		*High risk*	
Domain 4: Risk of bias in measurement of the outcome								
4.1 Was the method of measuring the outcome inappropriate?		x		x		x		x
4.2 Could measurement or ascertainment of the outcome have differed between intervention groups?		x		x		x		x
4.3 If N/PN/NI to 4.1 and 4.2: Were outcome assessors aware of the intervention received by study participants?	x		x		x		x	
4.4 If Y/PY/NI to 4.3: Could assessment of the outcome have been influenced by	x		x			x	x	

`

knowledge of intervention received?				
4.5 If Y/PY/NI to 4.4: Is it likely that assessment of the outcome was influenced by knowledge of intervention received?	x	x	x	x
Risk-of-bias judgement	*High Risk*	*Low Risk*	*Low Risk*	*High Risk*
Domain 5: Risk of bias in selection of the reported result				
5.1 Were the data that produced this result analysed in accordance with a pre-specified analysis plan that was finalised before unblinded outcome data were available for analysis?	x	x	x	x
Is the numerical result being assessed likely to have been selected on the basis of the results from:				
5.2 Multiple eligible outcome measurements (e.g. scales, definitions, time points) within the outcome domain?	x	x	x	x
5.3 Multiple eligible analyses of the data?	x	x	x	x
Risk-of-bias judgement	*Low Risk*	*Low Risk*	*Low Risk*	*Low Risk*
Overall Rating	High Risk	Low Risk	Low Risk	High Risk

Note: Y = Yes; PY = Probably Yes; PN = Probably No; N = No

`

Appendix D – Demographics Questionnaire

About you:

1. **Age:**

2. **Gender:**

Male		Female	
Other		Prefer not to say	

3. **Ethnicity:** (Drop down menu)

4. **What country are you currently living in?** (Drop down menu)

5. **What is your relationship to your child?**

Mother		Father		Primary Caregiver	

6. **Were you experiencing post-traumatic stress before your child's injury?**

Yes		No	

7. **Have you received therapy, counselling, or other support for the emotional impact your child's brain injury has had on you?**

Yes		No	

About your child who had a brain injury:

8. **What is your child's age now?**

9. **What is your child's gender?**

Male		Female	
Other		Prefer not to say	

10. **What is your child's ethnicity?** (Drop down menu)

`

11. How long has it been since your child acquired their injury? (Years / months)

12. What type of injury did your child acquire? [Note: there will be additional follow-on questions depending on the answer given to this question]

Non-traumatic Brain Injury:	
Anoxia (lack of oxygen to the brain)	
Infection / Encephalitis	
Stroke / Haemorrhage / Bleeding / Blood clot	
Tumour	
Traumatic Brain Injury	
Other (Please specify):	

13. For parents of children with TBI's only: **Please answer the following questions as well as you can. If you don't know or don't have the information, please don't worry. However, please do answer if you can, as this helps us understand the severity of the traumatic brain injury.**

Based on your child's medical reports immediately following the injury, was your child:

Unconscious for more than 30 minutes	
Unconscious for less than 30 minutes	
My child did not lose consciousness	

Unable to make new memories (in 'post-traumatic amnesia' or PTA) for more than 24 hours immediately after the injury	
Unable to make new memories (in 'post-traumatic amnesia' or PTA) for 2-4 hours immediately after the injury	
My child was able to make new memories, but appeared confused immediately after the injury	
Not known / Not Applicable	

`

Lowest reported Glasgow Coma Score (GCS):

My child had a GCS between 3 and 8	
My child had a GCS between 9 and 12	
My child had a GCS between 13 and 15	
Not known / not applicable	

14. Do you know which areas of the brain were worst affected by your child's injury? (tick all that apply):

	Sides of the brain	
	Left	Right
Frontal lobe		
Temporal lobe		
Parietal lobe		
Occipital lobe		
Brain stem		
Cerebellum		
Diffuse injury		

`

Appendix E – Posttraumatic Stress Disorder Checklist (PCL-C)

Below is a list of problems and complaints that people sometimes have in response to stressful life experiences. Please read each one carefully. Tick the box to indicate how much you have been bothered by that problem, with reference to your child's acquired brain injury.

No.	Response	Not at all (1)	A little bit (2)	Moderately (3)	Quite a bit (4)	Extremely (5)
1.	Repeated, disturbing *memories, thoughts, or images* of a stressful experience from the past?					
2.	Repeated, disturbing *dreams* of a stressful experience from the past?					
3.	Suddenly *acting* or *feeling* as if a stressful experience *were happening* again (as if you were reliving it)?					
4.	Feeling *very upset* when *something reminded* you of a stressful experience from the past?					
5.	Having *physical reactions* (e.g., heart pounding, trouble breathing, or sweating) when *something reminded* you of a stressful experience from the past?					
6.	Avoid *thinking about* or *talking about* a stressful experience from the past or avoid *having feelings* related to it?					
7.	Avoid *activities* or *situations* because they *remind you* of a stressful experience from the past?					
8.	Trouble *remembering important parts* of a stressful experience from the past?					
9.	Loss of *interest in things that you used to enjoy?*					
10.	Feeling *distant* or *cut* off from other people?					
11.	Feeling *emotionally numb* or being unable to have loving feelings for those close to you?					
12.	Feeling as if your *future* will somehow be *cut short*?					
13.	Trouble *falling* or *staying asleep*?					
14.	Feeling *irritable* or having *angry outbursts*?					
15.	Having *difficulty concentrating*?					
16.	Being *"super alert"* or watchful on guard?					
17.	Feeling *jumpy* or easily startled?					

`

Appendix F – Posttraumatic Growth Inventory (PTG-I)

Below is a list of statements. Please tick the box below to indicate the degree to which this change occurred as a result of your child's acquired brain injury.

0 = I did not experience this change as a result of my crisis.
1 = I experienced this change to a very small degree as a result of my crisis.
2 = I experienced this change to a small degree as a result of my crisis.
3 = I experienced this change to a moderate degree as a result of my crisis.
4 = I experienced this change to a great degree as a result of my crisis.
5 = I experienced this change to a very great degree as a result of my crisis.

Possible Areas of Growth and Change	0	1	2	3	4	5
1. I changed my priorities about what is important in life.						
2. I have a greater appreciation for the value of my own life.						
3. I developed new interests.						
4. I have a greater feeling of self-reliance.						
5. I have a better understanding of spiritual matters.						
6. I more clearly see that I can count on people in times of trouble.						
7. I established a new path for my life.						
8. I have a greater sense of closeness with others.						
9. I am more willing to express my emotions.						
10. I know better that I can handle difficulties.						
11. I am able to do better things with my life.						
12. I am better able to accept the way things work out.						
13. I can better appreciate each day.						
14. New opportunities are available which wouldn't have been otherwise.						
15. I have more compassion for others.						
16. I put more effort into my relationships.						
17. I am more likely to try to change things which need changing.						
18. I have a stronger religious faith.						
19. I discovered that I'm stronger than I thought I was.						
20. I learned a great deal about how wonderful people are.						
21. I better accept needing others.						

`

Appendix G – COPE Inventory (COPE)

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by ticking the box which is most appropriate to you, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU--not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

	I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
I turn to work or other substitute activities to take my mind off things				
I get upset and let my emotions out				
I try to get advice from someone about what to do				
I say to myself, "this isn't real"				
I admit to myself that I can't deal with it, and quit trying				

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I discuss my feelings with someone				
I use alcohol or drugs to make myself feel better				
I get used to the idea that it happened				
I talk to someone to find out more about the situation				
I daydream about things other than this				
I get upset, and am really aware of it				
I accept that this has happened and that it can't be changed				
I try to get emotional support from friends or relatives				
I just give up trying to reach my goal				
I try to lose myself for a while by drinking alcohol or taking drugs				

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I refuse to believe that it has happened				
I let my feelings out				
I talk to someone who could do something concrete about the problem				
I sleep more than usual				
I get sympathy and understanding from someone				
I drink alcohol or take drugs, in order to think about it less				
I give up at the attempt to get what I want				
I pretend that it hasn't really happened				
I go to the movies or watch TV, to think about it less				
I accept the reality of the fact that it happened				
I ask people who have had similar				

`

experiences what they did				
I feel a lot of emotional distress and I find myself expressing those feelings a lot				
I reduce the amount of effort I'm putting into solving the problem				
I talk to someone about how I feel				
I use alcohol or drugs to help me get through it				
I learn to live with it				
I act as though it hasn't even happened				

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Appendix H – Social Network Index (SNI)

Social Network Index

Instructions: This questionnaire is concerned with how many people you see or talk to on a regular basis including family, friends, workmates, neighbors, etc. Please read and answer each question carefully. Answer follow-up questions where appropriate.

1. Which of the following best describes your marital status?
   ___(1) currently married & living together, or living with someone in marital-like relationship
   ___(2) never married & never lived with someone in a marital-like relationship
   ___(3) separated
   ___(4) divorced or formerly lived with someone in a marital-like relationship
   ___(5) widowed

2. How many children do you have? (If you don't have any children, check '0' and skip to question 3.)

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

2a. How many of your children do you see or talk to on the phone at least once every 2 weeks?

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

3. Are either of your parents living? (If neither is living, check '0' and skip to question 4.)

___ (0) neither ___ (1) mother only ___ (2) father only ___ (3) both

3a. Do you see or talk on the phone to either of your parents at least once every 2 weeks?

___ (0) neither ___ (1) mother only ___ (2) father only ___ (3) both

4. Are either of your in-laws (or partner's parents) living? (If you have none, check the appropriate space and skip to question 5.)

___ (0) neither ___ (1) mother only ___ (2) father only ___ (3) both ___ (4) not applicable

4a. Do you see or talk on the phone to either of your partner's parents at least once every 2 weeks?

___ (0) neither ___ (1) mother only ___ (2) father only ___ (3) both

5. How many other relatives (other than your spouse, parents & children) do you feel close to? (If '0', check that space and skip to question 6.)

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

5a. How many of these relatives do you see or talk to on the phone at least once every 2 weeks?

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

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6. How many close friends do you have? (meaning people that you feel at ease with, can talk to about private matters, and can call on for help)

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

6a. How many of these friends do you see or talk to at least once every 2 weeks?

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

7. Do you belong to a church, temple, or other religious group? (If not, check 'no' and skip to question 8.)

_____ no _____ yes

7a. How many members of your church or religious group do you talk to at least once every 2 weeks? (This includes at group meetings and services.)

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

8. Do you attend any classes (school, university, technical training, or adult education) on a regular basis? (If not, check 'no' and skip to question 9.)

_____ no _____ yes

8a. How many fellow students or teachers do you talk to at least once every 2 weeks? (This includes at class meetings.)

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

9. Are you currently employed either full or part-time? (If not, check 'no' and skip to question 10.)

____ (0) no _____ (1) yes, self-employed _____ (2) yes, employed by others

9a. How many people do you supervise?

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

9b. How many people at work (other than those you supervise) do you talk to at least once every 2 weeks?

___0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

10. How many of your neighbors do you visit or talk to at least once every 2 weeks?

_____0 ___1 ___2 ___3 ___4 ___5 ___6 ___7 or more

`

11. Are you currently involved in regular volunteer work? (If not, check 'no' and skip to question 12.)

_____ no _____ yes

11a. How many people involved in this volunteer work do you talk to about volunteering-related issues at least once every 2 weeks?

____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

12. Do you belong to any groups in which you talk to one or more members of the group about group-related issues at least once every 2 weeks? Examples include social clubs, recreational groups, trade unions, commercial groups, professional organizations, groups concerned with children like the PTA or Boy Scouts, groups concerned with community service, etc. (If you don't belong to any such groups, check 'no' and skip the section below.)

_____ no _____ yes

Consider those groups in which you talk to a fellow group member at least once every 2 weeks. Please provide the following information for each such group: the name or type of group and the total number of members in that group that you talk to at least once every 2 weeks.

Group	Total number of group members that you talk to at least once every 2 weeks
1.	
2.	
3.	
4.	
5.	
6.	

Item 7 of this questionnaire was amended to read as follows: *"Do you belong to a Church, Temple, Mosque, Synagogue, meeting house or other religious group?".* This question was to increase the inclusivity of the questionnaire.

Item 12 of this questionnaire was also amended to read as follows: *"Do you belong to any groups in which you talk to one or members about group related issues at least once every two weeks? (Examples include social clubs, recreational groups, trade unions, commercial groups, professional organisations, groups concerned with children like the Parent-Teacher Association or Scouts, Guides or similar groups concerned with the community?"*

This question was also amended to increase understanding by including what PTA stood for. We also recognised that Scouts is accessible to females, so we removed the term "Boy" and added in "Guides" to increases inclusivity. It was not anticipated that these alterations would affect scoring or validation of this questionnaire.

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Appendix I – The Life Events Checklist (LEC-5)

Listed below are a number of difficult or stressful things that sometimes happen to people. For each event, check one or more of the boxes to the right to indicate that: (a) it happened to you personally; (b) you witnessed it happen to someone else; (c) you learned about it happening to close family member or a close friend; (d) you were exposed to it as part of your job (e.g. paramedic, police, military, or other first responder); (e) you're not sure if it fits; or (f) it doesn't apply to you.

Please answer the following questions with reference to events which have occurred [T1: during your lifetime / T2: within the last six months].

Event	Happened to me	Witnessed it	Learned about it	Part of my job	Not sure	Doesn't apply
1. Natural disaster (for example, flood, hurricane, tornado, earthquake)						
2. Fire or explosion						
3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)						
4. Serious accident at work, home, or during recreational activity						
5. Exposure to toxic substance (for example, dangerous chemicals, radiation)						
6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)						
7. Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)						
8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)						
9. Other unwanted or uncomfortable sexual experience						
10. Combat or exposure to a war-zone (in the military or as a civilian)						
11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war)						
12. Life-threatening illness or injury						
13. Severe human suffering						
14. Sudden violent death (for example, homicide, suicide)						
15. Sudden accidental death						
16. Serious injury, harm, or death you caused to someone else						
17. Any other very stressful event or experience						

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Appendix J – Participant Information Sheet (Time 1; T1)

PARTICIPANT INFORMATION SHEET

Study Title: Is there a relationship between Post-Traumatic Stress and Post-Traumatic Growth in Parents of children with an Acquired Brain Injury?

My name is Abigail Perkins, I am a Trainee Clinical Psychologist conducting this study as part of my Doctorate in Clinical Psychology at the University of East Anglia with Dr Fergus Gracey and colleagues.

I would like to invite you to take part in a study that investigates the relationship between post-traumatic stress and post-traumatic growth in parents after their child has acquired a brain injury. You do not have to make any immediate decisions about taking part in this online study. Please take your time to read the information below.

What is the purpose of this study?

This study aims to look at the relationship between post-traumatic stress and post-traumatic growth in parents following their child's acquired brain injury. When a child has a brain injury it can understandably be a traumatic event for some parents. How this effects people can vary. Some people might develop symptoms of post-traumatic stress including flashbacks, nightmares and feeling numb. Some might find new positive meanings in life despite their distress. This is called post-traumatic growth. In order to understand how to best support parents affected in this way, we are interested in finding out more about post-traumatic stress, post-traumatic growth and how they might be related.

Can I take part?

We are asking parents/primary caregivers of children aged 1-18 years who experienced an acquired brain injury at least 6 months ago to take part. Parents of children with any kind of ABI which is not getting worse, or where your child is not currently receiving major medical treatment (e.g. brain surgery, brain radiotherapy/chemotherapy) are eligible. We are inviting both parents of the same child to take part, but you can also take part without the child's other parent, this is your choice.

Sorry, but for this study we are not asking parents of children with progressive neurodegenerative illnesses to take part in the current study. Parents who find it difficult to understand written English would not be suitable for the current study.

`

Do I have to take part?

No, it is your choice whether you take part or not. If you decide to do so, please click next to continue. If you do not wish to participate, close this window. Please keep in mind that your participation in this study is voluntary so you can withdraw from the study at any time without explanation up until you submit your answers.

What do I have to do?

Please take your time to read and think about the information here before deciding to take part. If you decide you want to complete the survey, click “Next” at the bottom of this page.

This will take you to a consent page. Please read this carefully, and if you consent to participate click “Agree”.

Once you have clicked “Agree” the survey will start. You will need to complete all the questions. Please read the instructions for each set of questions. The questions will take approximately 30 minutes to complete. You will then need to submit your answers by clicking “Submit”.

We are also inviting you to participate in a second online survey in about 6 months’ time so we can see how things might have changed for you. Again, this will be in the form of an online survey. This second survey will take 10 minutes to complete. You will be given the option to “opt in” to this second survey at the end of the questionnaires. You will be asked to provide an email address so you can be contacted in 6 months’ time. Please keep in mind that this is optional, you do not have to take part in this second part of the study.

What are the possible disadvantages or risks of taking part?

We do not expect that the study will cause you any harm or risk by taking part. It may be possible that the study causes you to think about personal upsetting matters, including difficult thoughts and feelings. If this does happen, a list of support services will be provided which you can contact for extra support. If you withdraw from the study, this can be downloaded from XXX.

What will happen to my information?

Since you will not be asked to provide any personally identifiable information, all the data collected from this study will be anonymous. The data will be held by the research team at the University of East Anglia and may be shared securely with other researchers.

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You can withdraw from the study at any point without having to give a reason, up until you click submit. To do this simply close the browser or survey. However, you cannot withdraw once you have clicked submit as responses are anonymous, so it will not be possible to identify individual responses.

If you choose to opt in to the second part of the study, your email address will be held securely until the second part of the study has finished. It will then be confidentially deleted before data analysis.

What will happen to the results of this study?

We plan to present the results of this study at conferences, in a peer-reviewed journal and using social media. No participants will be identifiable in any of these cases. If you would like to receive a copy of the final findings, please contact abigail.perkins@uea.ac.uk with your request.

Who is organising the research?

This study is being organised by Abigail Perkins, Dr Fergus Gracey and Dr Kiki Mastronyannopoulou at the UEA. The study is also being supported by Dr Suzanna Watson and Dr Kate Psaila at the Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR).

Who has reviewed this study?

This study has been reviewed independently by colleagues and granted ethical approval by FMH Ethics committee at the University of East Anglia.

How can I find out more?

You can contact the research team:

Abigail Perkins abigail.perkins@uea.ac.uk

Dr Fergus Gracey F.Gracey@uea.ac.uk

If you have any concerns or complaints, please contact: Prof Niall Broomfield, Head of Department

N.Broomfield@uea.ac.uk

Thank you for taking the time to read this information.

`

Appendix K – Consent Form

CONSENT FORM

Project Title: Is there a relationship between Post-Traumatic Stress and Post-traumatic Growth in parents of children with an Acquired Brain Injury?

Name of Researchers: Abigail Perkins, Dr Fergus Gracey, Dr Kiki Manstroyannopoulou, Dr Suzanna Watson and Dr Kate Psaila.

Please read the following statements carefully:

I can confirm that I am a parent and/or primary carer of a child aged 1-18 years who acquired a brain injury at least 6 months ago and am eligible to participate.

I can confirm that I have read the information about this study. I have considered this information and have been provided with the opportunity to ask questions.

I understand that my involvement is strictly confidential, and that published data will have no identifiable information, and give permission for my anonymised data to be published in scientific publications, presentations and teaching.

I understand that that the information collected about me may be used to support other research in the future, and may be shared anonymously with other researchers, including those in other countries.

I understand that my data will be stored confidentially and securely by the research team at the University of East Anglia for a minimum period of six years.

I understand that my participation is voluntary, and I can withdraw from this study without reason, up until I click submit, by closing my browser.

I agree to take part in this study.

By clicking 'agree' you are confirming that you agree with all of the above statements. Once you have clicked agree, you will be taken to the first questionnaire of this study.

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Appendix L – Aftercare Sheet

Thank you for participating in this research.

The aim of this study is to investigate the relationship between post-traumatic stress and post-traumatic growth among parents of children with an acquired brain injury.

The results of this study will not include any information that is identifiable to you.

If you have any questions or would like a summary of the results of this study, please contact Abigail Perkins: abigail.perkins@uea.ac.uk.

It is possible that the study has caused you to think about personal upsetting matters. If you are feeling upset, distressed, or concerned about your family's wellbeing, please follow your normal route of accessing general healthcare advice. Or you can contact one of the following helplines:

United Kingdom support:

- **The Child Brain Injury Trust** on (**+44) 01869 341075** https://childbraininjurytrust.org.uk/
- **Samaritans** on **(+44) 116 123**
- **SANEline** on (**+44) 0300 304 700** (between 16:30 – 22:30) http://www.sane.org.uk/

United States support:

- **Mental Health America** on **(+1) 1-800-273-TALK (8255)** https://www.mhanational.org/
- **Brain line** for caregivers: https://www.brainline.org/caregivers
- **Brain Injury Association of America:** https://www.biausa.org/brain-injury/about-brain-injury

Australia support:

- **Synapse Australia** on **(+61) 1800 673 074** https://synapse.org.au/

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- **Samaritans** on **(+61) 134 247**
- **Lifeline** on **(+61) 131 114**

https://www.lifeline.org.au/

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Appendix M - Participant Information Sheet (Time 2; T2)

PARTICIPANT INFORMATION SHEET (T2)

Study Title: Is there a relationship between Post-Traumatic Stress and Post-Traumatic Growth in Parents of children with an Acquired Brain Injury?

My name is Abigail Perkins, I am a Trainee Clinical Psychologist conducting this study as part of my Doctorate in Clinical Psychology at the University of East Anglia with Dr Fergus Gracey and colleagues.

Thank you for considering taking part in the 'Time 2' part of this study, which will investigate the relationship between post-traumatic stress and post-traumatic growth in parents after their child has acquired a brain injury. All the information you read previously regarding this study also applies to this phase of the study. This time the survey will not take as long. There will be no new procedures, you will simply be repeating some of the surveys you kindly completed for us in Time 1. You do not have to make any immediate decisions about taking part in this online study. You will have the opportunity to read the information you read previously before consenting to take part in this study.

What is the purpose of this study?

This study aims to look at the relationship between post-traumatic stress and post-traumatic growth in parents following their child's acquired brain injury. When a child has a brain injury it can understandably be a traumatic event for some parents. How this effects people can vary. Some people might develop symptoms of post-traumatic stress including flashbacks, nightmares and feeling numb. Some might find new positive meanings in life despite their distress. This is called post-traumatic growth. In order to understand how to best support parents affected in this way, we are interested in finding out more about post-traumatic stress, post-traumatic growth and how they might be related.

This is data collection part two of this study.

Do I have to take part?

No, it is your choice whether you take part or not. If you decide to do so, please click 'Next' to continue. If you do not wish to participate, close this window. Please keep in mind that your participation in this study is voluntary so you can withdraw from the study at any time without explanation up until you submit your answers.

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What do I have to do?

Please take your time to read and think about the information here before deciding to take part. If you decide you want to complete the survey, click “Next” at the bottom of this page.

This will take you to a consent page. Please read this carefully, and if you consent to participate click “Agree”.

Once you have clicked “Agree” the survey will start. You will need to complete all the questions. Please read the instructions for each set of questions. The questions will take approximately 10 minutes to complete. You will then need to submit your answers by clicking “Submit”.

What are the possible disadvantages or risks of taking part?

We do not expect that the study will cause you any harm or risk by taking part. It may be possible that the study causes you to think about personal upsetting matters, including difficult thoughts and feelings. If this does happen, a list of support services will be provided of whom you can contact for extra support. If you withdraw from the study, this can be downloaded from XXX.

What will happen to my information?

The email address you provided for us to contact you on will be confidentially deleted before data analysis. We will not be able to trace your responses to your email address, all the data collected from this study will be anonymous. The data will be held by the research team at the University of East Anglia and may be shared securely with other researchers.

You can withdraw from the study at any point without reason, up until you click submit. However, you cannot withdraw once you have clicked submit as responses are anonymous, so it will not be possible to identify individual responses.

What will happen to the results of this study?

We plan to present the results of this study at conferences, in a peer-reviewed journal and using social media. No participants will be identifiable in any of these cases. If you would like to receive a copy of the final findings, please contact abigail.perkins@uea.ac.uk with your request.

Who is organising the research?

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This study is being organised by Abigail Perkins, Dr Fergus Gracey and Dr Kiki Mastronyannopoulou at the UEA. The study is also being supported by Dr Suzanna Watson and Dr Kate Psaila at the Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR).

Who has reviewed this study?

This study has been reviewed independently by colleagues and granted ethical approval by FMH Ethics committee at the University of East Anglia.

How can I find out more?

You can contact the research team:

Abigail Perkins Dr Fergus Gracey
abigail.perkins@uea.ac.uk F.Gracey@uea.ac.uk

If you have any concerns or complaints, please contact: Prof Niall Broomfield, Head of Department

N.Broomfield@uea.ac.uk

Thank you for taking the time to read this information

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Appendix N – Letter of Ethical Approval for Empirical Study

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Abigail Perkins

NORWICH MEDICAL SCHOOL
Bob Champion Research & Educational Building
Rosalind Franklin Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

Email: fmh.ethics@uea.ac.uk
www.med.uea.ac.uk

13th July 2021

Dear Abigail

Title: Is there a relationship between Post-Traumatic Stress and Post- Traumatic Growth in Parents of Children with an Acquired Brain Injury?

Reference: 2020/21-048

Thank you for your email of 29th June 2021 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you arrange to send us a report once your project is completed.

Yours sincerely

Dr Jackie Buck
Chair
FMH Research Ethics Committee