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Psychological and procedural distress following a young child's burn injury

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Abstract

Aim. The aim of this thesis is to understand the parent's role in pediatric procedural distress and recovery following a burn injury. Understanding how parents influence their child can inform future work to reduce pediatric procedural distress and improve recovery outcomes.

Literature Review. Following a pediatric burn injury, the associated wound care procedures can be potentially traumatic events that are often painful and distressing. Children under 6-years-old are particularly at risk of sustaining a burn injury, yet their pain-related procedural distress is also difficult to manage because of their young developmental level. Acute child and parental distress during the first weeks following a burn injury might impact the child's physical recovery, and the child and parent's ongoing psychological distress. There is some evidence to indicate that parents influence their child through their own psychological distress, and through parenting behavior. A review of the broader procedural distress empirical and theoretical literature led to the development of a new theoretical model for understanding the relationship between parent and child distress during medical procedures. The review also identified current gaps in the literature regarding current assessment tools and investigating the impact of procedural distress on long-term physical and psychological recovery. Therefore, the studies in this thesis aim to 1) develop and evaluate an appropriate observational assessment tool; 2) test the proposed theoretical model in a sample of parents and young children (1–6-years-old) during pediatric burn wound care; 3) investigate the parent's influence on their child's burn wound healing, and; 4) investigate the long-term (6-month) psychological outcomes of children and their parents following distressing burn wound care.

Study 1. The Burns-Child-Adult Medical Procedure Interaction Scale (B-CAMPIS) observational tool included nonverbal codes to assess parent-young child interactions during burn wound care. Parents of 87 children (1–6-years-old) were recruited at their child's first burn dressing change at the Pegg Leditschke Children's Burns Centre, Queensland Children's Hospital, Brisbane, Australia. Inter-coder reliability was good to excellent. Convergent and incremental validity was demonstrated through correlations with other previously validated observational parent-child behavior measures, and parent- and nurse-reported measures of the child's procedural pain and fear. Discriminant validity showed greater variation. The results indicate overall that the B-CAMPIS is a reliable and valid tool for parent-child interactions during burn wound care.

Study 2. The proposed theoretical model of the relationship between parent and child distress was tested on 87 families undergoing the child's first burn dressing change. Parents reported injury-related posttraumatic stress symptoms, pre-procedural fear, general anxiety/depression symptoms, and guilt before the first dressing change. Parent-child behavior was observed during the first

dressing change. Mediation analyses identified three indirect effects. Parental posttraumatic stress symptoms predicted more child distress, mediated through parental distress-promoting behavior. Parental guilt predicted more child distress, mediated through parental distress-promoting behavior. Parental general anxiety/depression symptoms predicted less child coping, mediated through less parental coping-promoting behavior. The proposed model was updated to reflect that parents with posttraumatic stress affect their child differently compared to parents with anxiety/depression symptoms during pediatric burn wound care.

Study 3. Research has established connections between stress and delayed wound healing. A model of the relationship between the child and parents' stress and re-epithelialization (wound healing) following pediatric burn injury was presented and tested on 83 families of young children (1–6-years-old). Time to re-epithelialization was obtained from medical charts. After the effects of injury severity and procedural pain, parental posttraumatic stress symptoms accounted for 5% of the additional variance in time to re-epithelialization. This finding equated to a one posttraumatic stress symptom increase in parents predicting a 1.36 day delay in the child's re-epithelialization. Potential mechanisms for this finding include genetic influences of stress and changes to parent-child interactions following the burn injury.

Study 4. The prevalence of psychological impairment of children and their parents at 6 months post-injury was investigated, and if initial procedural distress influenced these outcomes. Forty-three parents responded to a questionnaire regarding the child's posttraumatic stress symptoms, behavioral problems, health-related quality of life, and current pain, and the parents' own posttraumatic stress symptoms, parenting stress, and parenting style. Low levels of impaired functioning were reported. The presence of parental anxiety/depression symptoms at the first dressing change predicted lower child emotional health-related quality of life at 6 months, after controlling for current parenting stress. Secondly, higher procedural pain at the first dressing change predicted more overprotective parenting behavior at 6 months, after controlling for current child behavioral problems.

Conclusions. Overall, the findings of the thesis provide compelling evidence that parental acute psychological distress plays an integral role for the child's 1) experience of wound care, 2) rate of re-epithelialization, and 3) psychological recovery. Beyond the theoretical advances, these findings have implications for the clinical treatment of children undergoing burn dressing changes, and the development of psycho-behavioral interventions to increase support for parents during the acute phase of burn re-epithelialization.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, financial support and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my higher degree by research candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications during candidature

Publications included in this thesis

1. Brown, E. A., De Young, A., Kimble, R., & Kenardy, J. (2018). Review of a parent's influence on pediatric procedural distress and recovery. *Clinical Child and Family Psychology Review, 21*(2):224-245. doi: 10.1007/s10567-017-0252-3

2. Brown, E. A., De Young, A. C., Kimble, R., & Kenardy, J. (2018). Development and validity of the Burns-Child-Adult Medical Procedure Interaction Scale (B-CAMPIS) for young children. *Burns, 45*(1):76-87. doi: 10.1016/j.burns.2018.08.027

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1. Brown, E. A., De Young, A. C., Kimble, R., & Kenardy, J. (under review). The role of parental acute psychological distress in paediatric burn re-epithelialisation.

Other publications during candidature

Journal articles

1. Christie, H., Talmon, A., Schäfer, S.K., de Haan, A., Vang, M., Haag, K., Gilbar, O., Alisic, E., & Brown, E.A. (2018). The transition to parenthood following a history of childhood maltreatment: A review of the literature on prospective and new parents' experiences. *European Journal of Psychotraumatology. 8:* sup7. doi: 10.1080/20008198.2018.1492834

2. Kenardy, J., Edmed, S., Shourie, S., Warren, J., Crothers, A., Brown, E.A., Cameron, C., & Heron-Delaney, M. (2018). Changing patterns in the prevalence of Posttraumatic Stress Disorder, Major Depressive Episode and Generalized Anxiety Disorder over 24 months following a Road Traffic Crash: Results from the UQ SuPPORT Study. *Journal of Affective Disorders, 236*: 172-179. doi: 10.1016/j.jad.2018.04.090

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Conference abstracts

1. Brown, E. A., Kenardy, J., Kimble, R., & De Young, A. (Nov 2017). Acceptability of Take Six video resource for parents of children undergoing burn dressing changes (*Poster*). Child Health Queensland Research Symposium, Brisbane, QLD.

2. Brown, E. A., Kimble, R., De Young, A., & Kenardy, J. (Oct 2017). Pilot Intervention: Addressing parent distress during paediatric burn dressing changes (*Poster*). International Forum for Pediatric Pain, Halifax, Canada.

3. Brown, E.A., De Young, A., Kimble, R., & Kenardy, J. (Oct 2017). How to support parents during young paediatric dressing changes (*Oral*). Australia New Zealand Burn Association Annual Meeting, Adelaide.

4. Brown, E.A., De Young, A., Kimble, R., & Kenardy, J. (Sept 2017). Help the parent, help the child: How to support parents during young paediatric dressing changes (*Oral*). European Burn Association Biannual Meeting, Barcelona, Spain.

5. Brown, E.A., Perry-Parrish, C., Egberts, M., Verkaik, D., & Senneseth, M. (Aug 2017). Understanding the psychosocial impact of medical trauma on the family (*Oral*). European Conference on Developmental Psychology, Utrecht, The Netherlands.

6. Brown, E.A., Kenardy, J., & Chambers, C. (Jul 2017). Mobilizing parents to reduce pediatric pain and beyond (*Oral*). International Society for Pediatric Pain, Kuala Lumpur, Malaysia.

7. Brown, E.A., Kenardy, J., Kimble, R., & De Young, A. (Jun 2017). Novel approaches to assessment and intervention for children and parents in pediatric health care settings (*Oral*). European Society for Traumatic Stress Studies Biannual Meeting, Odense, Denmark.

8. Brown, E.A., Kenardy, J., De Young, A., & Kimble, R. (Apr 2017). Painful implications of parent's distress during young paediatric burns medical procedures (*Oral*). Australian Pain Society, Adelaide.

9. Brown, E.A., Kenardy, J., De Young, A., & Kimble, R. (Nov 2016). Anxious mum, anxious child: The impact of parent distress during medical procedures (*Oral*). CHQ Research Symposium, Brisbane.

10. Brown, E.A., Kenardy, J., De Young, A., & Kimble, R. (Oct 2016). Observations from the paediatric outpatients unit: Parent emotions, behaviour and child distress (*Oral*). Australia and New Zealand Burn Association Annual Conference, Auckland, New Zealand.

11. Brown, E.A., Kenardy, J., De Young, A., & March, S. (Sept 2016). Identifying and addressing experiences in pediatric health care (*Oral*). Australasian Conference on Traumatic Stress, Gold Coast.

12. Brown, E.A., Kenardy, J., Kimble, R., & De Young, A. (Jun 2016). An observational study of the role of parent distress and behaviour during a medical procedure following paediatric burn injury in influencing child and parent psychological, and child physical recovery outcomes (*Oral*). Childhood Trauma Conference, Melbourne.

13. Brown, E.A., Kenardy, J., Kimble, R., & De Young, A. (Nov 2015). How parent distress and behaviour during a medical procedure following paediatric burn injury influences child and parent psychological outcomes, and physical recovery (*Poster*). Child Health Queensland Research Day, Brisbane, QLD.

14. Brown, E.A., Kenardy, J., Shourie, S., Crothers, A., Warren, J., Cameron, C., & Heron-Delaney, M. (Nov 2015). Change in prevalence of psychiatric diagnoses over 2 years following a road traffic crash: Results from the UQ SuPPORT Study (*Poster*). International Society for Traumatic Stress Studies Annual Meeting, New Orleans, USA.

15. Kenardy, J., Heron-Delaney, M., Warren, J., & Brown, E. A. (Nov 2014). Effect of mental health on long-term recovery following a Road Traffic Crash: Results from UQ SuPPORT study (*Oral*). Australian Compensation Health Compensation Forum, Melbourne, VIC.

16. Brown, E. A., Kenardy, J. A., & Dow, B. L. (Nov 2014). PTSD perpetuates pain in children with traumatic brain injury (*Oral*). International Society of Traumatic Stress Studies Annual Meeting, Miami, USA.

17. Brown, E. A., Kenardy, J. A., & Dow, B. L. (Sept 2014). PTSD perpetuates pain in children with traumatic brain injury (*Oral*). Australasian Conference on Traumatic Stress, Melbourne, VIC.

Media

1. The Conversation: Parents' reactions can lessen or worsen pain for injured kids (Apr 2017). 46,256 readers. This article was republished or summarised on ABC Online (269,980 daily visitors), Sydney Morning Herald (180,180 daily visitors), The Age (97,390 daily visitors), Sky News Australia (40,640 daily visitors), Yahoo! News Australia (94,360 daily visitors), Yahoo! Prime7, WA Today (8,490 daily visitors), The North West Star, Getlifestyle, Medical Xpress, and Health Canal.
2. UQ News Press Release: Parents can help soothe burns treatment stress (Apr 2017)
3. Interview for Brisbane Times Online Newspaper: Distraction the key to calming children during procedures: study (Apr 2017) 26,720 daily visitors
4. Facebook: UQ Medicine –Research Short video posted on (Apr 2017)
5. Radio interview for ABC Adelaide, (Apr 2017), 22,000 listeners
6. Radio interview for ABC Sydney, (Apr 2017), 55,000 listeners
7. Radio interview for ABC Riverlands, (Apr 2017)
8. UQ News Press Release: Study could lead to better treatment for child brain injuries (Sept 2014)

Contributions by others to the thesis

Supervisors

Professor Justin Kenardy: Assisted with the conception and design of the project, provided ongoing supervision regarding data collection and interpretation of the analyses, provided constructive feedback on the co-authored manuscripts, and provided critical revision of thesis.

De Alexandra De Young: Assisted with the conception and design of the project, provided ongoing supervision regarding data collection and interpretation of the analyses, provided constructive feedback on the co-authored manuscripts, and provided critical revision of thesis.

Professor Roy Kimble: Contributed to the conception and design of the project, facilitated recruitment at the Pegg Leditschke Children's Burns Centre, provided ongoing supervision regarding interpretation of the analyses, and provided constructive feedback on the co-authored manuscripts.

Other contributors

Ms Anne Bernard: Provided statistical advice and feedback on one of the empirical chapters.

Ms Jacelle Warren: Provided statistical advice.

Ms Gillian Montague: Assisted with data transcription and data entry.

Ms Krittika Vongkiatkajorn: Assisted with data transcription.

Mrs Jennifer Brown: Assisted with data transcription.

Statement of parts of the thesis submitted to qualify for the award of another degree

No works submitted towards another degree have been included in this thesis.

Research involving human or animal subjects

This study was approved by the University of Queensland Human Research Ethics (approval number 2015000623) and the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (approval number HREC/15/QRCH/27). Queensland Children's Hospital institutional approval was also attained (reference number SSA/15/QRCH/63). Approval letters can be found in Appendix A.

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Keywords and classifications

Keywords

Parent, child, burn injury, psychological distress, behavior, procedural distress, recovery

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 111717, Primary Health Care, 20%

ANZSRC code: 170102, Developmental Psychology and Ageing, 40%

ANZSRC code: 170106, Health, Clinical and Counselling Psychology, 40%

Fields of Research (FoR) Classification

FoR code: 1117, Public Health and Health Services, 20%

FoR code: 1701, Psychology, 80%

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List of abbreviations used in the thesis

BAADS	Behavioral Approach-Avoidance and Distress Scale
BBDS	Brief Behavioral Distress Scale
B-CAMPIS	Burns-Child-Adult Medical Procedure Interaction Scale
BMA	Bone Marrow Aspiration
CAMPIS	Child-Adult Medical Procedure Interaction Scale
CAMPIS-R	Child-Adult Medical Procedure Interaction Scale-Revised
CAMPIS-SF	Child-Adult Medical Procedure Interaction Scale-Short Form
CBCL	Child behaviour checklist
CHEOPS	Children's Hospital of Eastern Ontario Pain Scale
COMFORT-B	COMFORT Behavior scale
DPIS	Dyadic Pre-Stressor Interaction Scale
DSM-IV	Diagnostic and Statistical Manual for Mental Disorders, 4th Edition
DSM-V	Diagnostic and Statistical Manual for Mental Disorders, 5th Edition
FLACC	Face, Legs, Arms, Consolability, Cry
GGS	Global Guilt Scale
HRQL	Health-related quality of life
ICC	Intra-class Correlation
IM	Intramuscular injection
IQR	Interquartile Range
LP	Lumbar Puncture
MAISD	Measure of Adult and Infant Soothing and Distress
m-YPAS	Modified Yale Preoperative Anxiety Scale
N	Nurse-reported measure
NPRS	Numerical Pain Rating Scale
NV	Nonverbal
O	Observer-reported measure
OSBD	Observation Scale of Behavioral Distress
P	Parent-reported measure
PACBIS	Perioperative Adult Child Behavior Interaction Scale
PAB	Pediatric Anesthesia Behavior
PBS	Parent Behavior Scale
PBRS	Procedure Behavior Rating Scale
P-CAMPIS	Perioperative Child-Adult Medical Procedure Interaction Scale

PC-PTSD	Primary Care Posttraumatic Stress Disorder screen
PDS	Posttraumatic Stress Diagnostic Scale
PedsQL	Pediatric Quality of Life Inventory
PHQ-4	Patient Health Questionnaire-4
PIPS	Post-trauma Inventory of Parenting Style
PLCBC	Pegg Leditschke Children's Burns Centre
POCIS	Pain Observation Scale for Young Children
PSI-SF	Parenting Stress Index-Short Form
PTSD	Posttraumatic stress disorder
PTSS	Posttraumatic stress symptoms
SEIFA	Socio-economic Indexes for Australia
V	Verbal
VAS-A	Visual Analogue Scale-Anxiety
YCPC	Young Child PTSD Checklist
YPAS	Yale Preoperative Anxiety Scale
%TBSA	Percentage of total body surface area

Preface

Research has identified that parental behavior influences child procedural distress (e.g., Blount et al., 1989). However, parental psychological distress has not been investigated in the context of pediatric procedural distress relating to a serious medical condition. A secondary body of research has investigated parent and child psychological distress in the wake of a trauma such as a pediatric injury (Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016), and current thought is that parental psychological symptoms contribute to or maintain child psychiatric symptomology (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Researchers have hypothesized that the mechanism of influence of parent to child is a combination of genetic and behavioral factors (Drury, Brett, Henry, & Scheeringa, 2013; Saxe, Stoddard, Chawla, et al., 2005). To the same end, pediatric healthcare professionals anecdotally recognize that "anxious children" often present with "anxious parents".

Burn wound care is a particularly painful medical procedure. Wound care involves repeatedly removing the dressing, exposing the nerve endings to air, debriding (removing necrotic tissue and blisters, remaining foreign matter), and touching to assess severity, until re-epithelialization (wound healing). In general, it is difficult to achieve adequate burn wound care analgesia because burn injuries cause changes in physiology that increase pain sensitivity (Connor-Ballard, 2009; Sharar et al., 2008), and reduce the effectiveness of pharmacologic intervention (due to drugs being processed more quickly by the patient's metabolism) (Cooper & Pavlin, 1990). Considering young children (1–6-years-old) are at high risk of sustaining a burn injury (Stockton, Harvey, & Kimble, 2015), and the above described research findings, the parent's behaviors during their young child's burn wound care may be particularly influential.

This thesis aimed to investigate the potential behavioral mechanism of influence between parent and child, and parental psychological contributors, by developing theoretical and empirical understanding of this phenomenon. Understanding the ways in which a parent's psychological distress influences their child can guide the development of future interventions.

A number of steps are required prior to the development of an intervention: 1) an observational measure to assess parent-young child interactions during burn wound care; 2) a theoretical understanding of the relationship between parental psychological distress and child procedural distress; 3) an empirical evaluation of the theoretical model, and; 4) an investigation of parent and child long-term outcomes (both physical and psychological) following a distressing medical procedure.

This thesis

This thesis aims to understand the influence of parental psychological distress on young child (1–6-years-old) procedural coping and distress behavior, re-epithelialization, and parent and child psychological outcomes following a pediatric burn injury. The empirical chapters of the thesis are based on data provided by a cohort of families. Participating families provided questionnaire, observational, medical, and longitudinal follow up data.

1. Chapter 1 provides an overview of the boarder literature for the parent-related risk factors for pediatric procedural distress (not specifically burn wound care). A theoretical model was developed, and current gaps in the literature were identified, and shaped the remaining thesis chapters. The theoretical model proposed that parental psychological distress would lead to increased child procedural distress through reduced parental sensitivity. This chapter has been published in *Clinical Child and Family Psychology Review* (E. A. Brown, De Young, Kimble, & Kenardy, 2018b).
2. Chapter 2 is an overview of the research methodology used in this thesis and narrows the focus to the context of burn wound care. One observational study was conducted, with longitudinal follow up on a pediatric burn population. Specifically, families were observed at their child's first burn dressing change, and prospectively followed up 6 months after the injury.
3. Chapter 3 comprises of an empirical study describing the development and validation of a measure of young child and parent behavior during pediatric burn wound care. Based on previous work, the Burns-Child-Adult Medical Procedure Interaction Scale (B-CAMPIS) incorporated nonverbal behaviors that indicated child coping and distress behavior, as well as parenting behaviors that influenced child coping and distress behavior. This chapter has been published in *Burns* (E. A. Brown, De Young, Kimble, & Kenardy, 2018a).
4. Chapter 4 is an empirical study of the relationship between parental acute psychological distress and child procedural behavior, as mediated by parental behavior in the context of burn wound care. It investigated the unique contributions of range of psychological distress. The study tested the theoretical model that was proposed in Chapter 1. An updated model relevant to pediatric burn wound care was presented. This chapter has been published in the *Journal of Clinical Psychology in Medical Settings* (E. A. Brown, De Young, Kimble, & Kenardy, 2019).
5. Chapter 5 comprises of an empirical study investigating the influence of parent and child acute psychological and procedural distress on re-epithelialization. Psychological stress has previously been related to physiological changes that impede wound healing, however, research has not before investigated the influence of caregiver psychological stress on re-

epithelialization. Possible genetic and behavioral mechanisms are proposed. This chapter is currently under review for possible publication.

6. Chapter 6 is an empirical study investigating prevalence of 6-month parent and child psychological outcomes, and the potential the influence of initial procedural distress. Data were prospectively collected at a 6 month follow up of children and families. Child outcomes included child posttraumatic stress symptoms, behavioral problems, health-related quality of life, and pain. Parent outcomes included posttraumatic stress symptoms, parenting stress, and parenting style.
7. Chapter 7 discusses the main findings of the thesis, in relation to overall limitations, and research and clinical implications. Underlying assumptions are raised, as well as suggestions for future intervention with parents and healthcare professionals.

The University of Queensland supports PhD candidates who wish to include published works in their thesis. In this thesis, several of the chapters have been written as journal articles. Chapters consist of peer-reviewed published journal articles (Chapter 1, Chapter 3, and Chapter 4), manuscripts currently under review (Chapter 5), and chapters without intent to publish (Chapter 2, Chapter 6, and Chapter 7). This thesis is presented in American spelling for consistency with the published/under review journal articles with the exception of Chapter 5. In Chapter 1, the review of literature is broad (i.e., all pediatric medical procedures). In comparison, the empirical chapters (Chapters 3–6) are specific to the field of pediatric burn wound care. To avoid repetition, parts of the manuscripts have been omitted. This omission is mainly evident in the Methods sections of the empirical articles: Explanations of the B-CAMPIS were omitted from Chapters 4–6 (the reader is directed to Chapter 3), and explanations of parental acute psychological distress variables were omitted from Chapters 5–6 (the reader is directed to Chapter 4). Chapter 6 has avoided repetition of the study protocol.

Terminology used in this thesis

The term ‘distress’ has been used to describe different constructs within the different fields of literature cited. For example, it can relate to 1) psychological stress, 2) situational stress, or 3) behavioral indication of procedural pain and/or fear. To clarify terminology in this thesis, parents reporting psychological or situational stress will be defined as ‘parental acute psychological distress’. Children displaying pain and/or fear behavior will be defined as ‘procedural distress’, or ‘distress behavior’ when referring to the CAMPIS-R category by Blount et al. (1997).

Pain, fear, and anxiety are of themselves separate yet related constructs (Barlow, 2002) that require further clarification due to interchangeable use in the procedural pain literature. Pain is an unpleasant subjective experience connected to bodily damage, while fear is an alarm reaction to an

imminent threat (resulting in avoidant or hypervigilant behavior), and procedural anxiety is negative emotion in relation to a future threat (resulting in escape behavior) (McMurtry et al., 2015). This thesis attempts to use the correct terminology as much as possible while remaining accurate to the sources cited.

Chapter 1. Review of a parent's influence on pediatric procedural distress and recovery

Brown, E.A., De Young, A., Kimble, R., & Kenardy, J. (2018). Review of a parent's influence on pediatric procedural distress and recovery. *Clinical Child and Family Psychology Review,* 21(2):224-245. doi: 10.1007/s10567-017-0252-3

1.1 Contribution to authorship

The design of this review paper was shared between myself (50%) and my supervisors. I was 100% responsible for writing the paper, and my supervisors provided detailed feedback.

1.2 Preamble

The aim of this chapter is to provide a summary of the background and rationale which underpins the research questions explored in this thesis. The review identified research gaps and relevant theoretical models to guide the thesis. Specifically, this chapter reviews 1) pediatric procedural pain and distress; 2) risk factors of pediatric procedural pain and distress (including parent-related risk factors); 3) child and parent outcomes of pediatric procedural distress; 4) relevant theories; 5) limitations of available measures for assessing parent and young child procedural distress, and; 6) non-pharmacological interventions for reducing procedural distress (including parent-focused interventions). This chapter comprises of a paper that has been published in *Clinical Child and Family Psychology Review*, and is presented with minor modifications.

1.3 Background

Young children (0–4-years-old) are significantly overrepresented in the healthcare system. Annually in Australia, significant proportions of young children are admitted to hospital (22%) and/or receive outpatient care (83%) due to illness or injury (Australian Bureau of Statistics, 2015; Australian Institute of Health and Welfare, 2016a, 2016b). Young children are more likely to become ill because they have vulnerable immune systems (Australian Institute of Health and Welfare, 2014; World Health Organisation, 2017), or sustain an injury because they start to explore their surrounds without an awareness of potential dangers (Australian Bureau of Statistics, 2007; Bugeja & Franklin, 2005; Schmertmann, Williamson, Black, & Wilson, 2013). During hospitalization, children receive numerous medical procedures: Pediatric inpatients experience an average of 6.3 painful procedures per day (Stevens et al., 2011). Beyond procedures relating to injury or illness, young children can also experience pain during immunization procedures. The majority of research on procedural pain-related distress has been conducted in this context and although there are sample differences, findings are still relevant for this review.

Medical procedures are often painful events for young children. One of many potentially modifiable factors that influence procedural pain is the parent and parenting behaviors. Pain management is important for the child's acute and long-term physical and psychological outcomes, and parents can also experience lasting psychological effects from witnessing their child in pain (Bakker, Van Loey, Van Son, & Van der Heijden, 2010; McGarry et al., 2015). The focus of this empirical and theoretical review is to explore the parent's role in supporting their child during pediatric medical procedures and develop a theoretical framework for understanding the impact of parental psychological distress on parenting behavior. On this basis, we make recommendations regarding 1) developing valid assessment tools; 2) testing our theoretical model; 3) researching long-term outcomes of procedural distress, and; 4) developing effective interventions to improve pediatric medical experiences for the child and the family.

1.4 Procedural pain

Young children do not always receive adequate procedural pain management (see Blount, Piira, Cohen, & Cheng, 2006; Howard, 2003). It can be difficult to assess and manage pain in young children for a number of reasons (McGrath & Frager, 1996). Firstly, young children cannot verbally communicate pain severity. Therefore, adults are required to make judgments of severity based on behavioral distress. However, young children also express fear through behavioral distress, and it is difficult to differentiate distress from pain (Shacham & Daut, 1981). Presuming a child's distress is fear-driven rather than pain-driven can lead to less-than-optimal pain management (McGrath &

Frager, 1996). Expressions of distress can also lead to health professionals developing negative perceptions of the child and therefore less pain management (McGrath & Frager, 1996). In addition, young children have not yet developed metacognitive skills to engage in self-coping strategies to moderate pain experiences. For example, toddlers can engage in non-cognitive coping strategies such as seeking comfort, but only older children can understand complex pain-related concepts and use cognitive coping strategies (McGrath & Frager, 1996). Furthermore, young children are unlikely to understand procedural pain as necessary, helpful or temporary. Instead, children commonly understand pain to be a punishment for misbehaving (Gaffney & Dunne, 1987). All these factors lead to young children being at greater risk of higher procedural pain (Young, 2005). As primary caregivers, parents may be able to better interpret their young child's pain signals and help manage the pain.

Procedural pain can negatively affect future experiences of pain. Future experiences include an increased fear of pain and reduced pain threshold. In adults, general practice patients who reported a previous traumatic needle event also reported an increased fear of needles, stronger vasovagal response, and a higher likelihood to avoid future medical treatment involving needles, compared to patients without a previous traumatic needle event (Wright, Yelland, Heathcote, Ng, & Wright, 2009). In children, pain memory (Young, 2005) and conditioning (Thurber, Martin-Herz, & Patterson, 2000) are thought to increase anticipatory fear of procedural pain. A painful experience may also reduce a child's pain threshold. In animal models, mature rats who experienced pain as rat pups had altered nociceptive neuronal circuits and greater distress responses, compared to mature rats without prior pain experiences (Ruda, Ling, Hohmann, Peng, & Tachibana, 2000). Similarly in humans, male infants who underwent circumcision (un-medicated) displayed greater negative affect during subsequent vaccinations, compared to female infants (Taddio, Goldbach, Ipp, Stevens, & Koren, 1995; Taddio, Katz, Ilersich, & Koren, 1997). These results indicate a pain experience negatively affects future pain experiences, and interventions designed to reduce pain are valuable for improving immediate and future medical procedure experiences.

Procedural pain management also appears important for physical recovery. Pain is inherently a stressful experience (Millan, 1999), and stress may underlie the pain-healing relationship. A meta-analysis of 22 studies found a medium effect for increased psychological stress being associated with delayed wound healing in adults (Walburn, Vedhara, Hankins, Rixon, & Weinman, 2009). In animals, environmental stress was associated with increased corticosterone and hypothalamic-pituitary-adrenal activation, and delayed wound healing (French, Matt, & Moore, 2006; J. F. Sheridan, Padgett, Avitsur, & Marucha, 2004). In children, higher pain reports during dressing changes were related to delayed burn wound healing (N. J. Brown, Kimble, Gramotnev, Rodger, &

Cuttle, 2014; K. Miller, Rodger, Kipping, & Kimble, 2011). Mechanisms of the stress-healing relationship include biological changes such as changes in cortisol levels, immune functioning, and inflammatory responses; and behavioral changes, for example reduced adherence to wound care (Chen, Maidof, & Lyga, 2015; Upton & Solowiej, 2010). Although research designs employed limit causal inferences, the evidence indicates experiencing greater pain is associated with delayed wound healing.

1.5 Procedural distress

While there are limitations in eliminating procedural pain in young children, there is potential to address the related distress. Defined as a strong negative reaction to a medical procedure, 50–70% of children experience severe procedural distress (Kain, Mayes, O'Connor, & Cicchetti, 1996). For children under 5-years-old who have more trouble accurately self-reporting pain intensity, distress is often used as a proxy. Pain-related distress has been measured using behavioral and physiological assessment tools (Finley & McGrath, 1998; McGrath, Latimer, Finley, & Chambers, 2009). There are limitations with both types of assessment. Physiological and behavioral measures do not always reflect pain intensity as they can also reflect anxiety or fear (Cohen, Blount, Cohen, & Johnson, 2004; Owens, 1986). Further, pain is not always expressed behaviorally, as cultural expressions of pain can differ (Strong, Nielsen, Williams, Huggins, & Sussex, 2015). However, pain-related distress is most commonly identified through behavior (see von Baeyer & Spagrud, 2007, for a review). Distress can be observed in body movements (rigidity, withdrawing, kicking, thrashing, jerky movement, twisting, back arching), facial expressions (squeezed eyes, cupped tongue), vocalizations (cry, scream), and verbalizations (verbal resistance) (Craig, Lilley, & Gilbert, 1996; Grunau & Craig, 1987). Procedural distress has been positively related with uncooperativeness and pain (Klorman, Michael, Hilpert, & Sveen, 1979), and future procedural distress (Lumley, Melamed, & Abeles, 1993). Whether the behavior is due to pain or fear, reducing child distress should make medical procedures more tolerable for the child and the family.

Procedural distress can also be considered a child's response to a potentially traumatic event. As young children do not have the cognitive capacity to understand that a procedure is necessary, helpful, and temporary, they can perceive the procedure as a negative or life-threatening event. Perceived threat to life is required to develop posttraumatic stress symptoms (PTSS) (American Psychiatric Association, 2013). The pediatric posttraumatic stress literature has identified that unintentional injuries and ongoing injury/illness-related medical procedures can contribute to PTSS development (Price et al., 2016). Distress during medical procedures can be a result of trauma from the illness or injury diagnosis, be a trauma or pain reaction during the procedure/s, or accumulate across both of these potentially traumatic events. Identifying risk factors and outcomes of

procedural distress can guide interventions for reducing acute and chronic psychological distress in pediatric populations.

1.6 Risk factors for procedural distress

In addition to pharmacological intervention, a range of pre-existing and procedural factors can influence procedural pain-related distress (for a full review, see Young, 2005). Some risk factors are considered stable (not alterable but identification can lead to additional support), while others are modifiable (of interest to researchers and clinicians because intervention is possible). Pre-existing risk factors that are stable include younger age, non-Anglo ethnicity, and female sex (Young, 2005). Pre-existing risk factors can be addressed over time include medical fears, child's state anxiety, decreased sense of control, and use of pain-coping behavior (Young, 2005). Modifiable risk factors relate to how the procedure is conducted, such as medical staff providing inadequate preparation/information, a noisy environment, and parent or medical staff using verbal distress-promoting behavior (i.e., reassurance). Research has consistently demonstrated a relationship between child and parent distress behavior and that young children are likely to be especially receptive to information provided by parents during a medical procedure. Therefore, the remainder of the review will focus on the parent's sensitive parenting behavior and psychological distress as potentially modifiable risk factors for reducing child procedural distress.

1.6.1 Parent-related risk factors for procedural distress

Children experience medical procedures within the context of their family. A child's coping strategies, experiences, and expectations are thought to be related with that of their parents' (Bowen, 1966). Not all hospitals advocate for parents to be present during invasive medical procedures, although research has shown parents generally prefer to be present (Egberts, de Jong, Hofland, Geenen, & Van Loey, 2018). The effect of parental presence on child distress during a child's medical procedure has been studied for over 5 decades. Parental presence has been found to reduce child distress (i.e., Schulman, Foley, Vernon, & Allan, 1967), although findings are not consistent (for a systematic review, see Piira, Sugiura, Champion, Donnelly, & Cole, 2005). This inconsistency suggests parents can differentially influence their child during a medical procedure. The effect of parental presence likely depends on many individual factors, including the parent's sensitivity to the child's need for emotional co-regulation, and the parent's own psychological distress related to the child's injury or illness. These factors are reviewed below.

1.6.2 Parental sensitivity

Parental (or primary caregiver) sensitivity is important for providing a young child with emotion co-regulation (Camras, Sachs-Alter, & Ribordy, 1996; Cassidy, 1994; Gottman, Katz, & Hooven,

1997; Kopp, 1989). The attachment literature defined parental sensitivity as the ability to "perceive her baby's signals, interprets them accurately, and responds appropriately and promptly" (p.142. Ainsworth, Blehar, Waters, & Wall, 1978). Parents vary in sensitivity (Biringen & Easterbrooks, 2012; Biringen, Robinson, & Emde, 1998; Slade, 2005), which has been assessed through responses to a semi-structured interview (Slade, 2005), verbal reflections (Daley, Sonuga-Barke, & Thompson, 2003), or observed behaviors (Biringen et al., 1998; Crowell, Feldman, & Ginsberg, 1988). The observational research involves laboratory-based manipulated stress-inducing tasks (i.e., packing up toys) wherein the sensitivity and effectiveness of parenting behavior is judged in relation to the infant's reactions. Higher parental sensitivity has been associated with better child outcomes including secure attachment (Meins, Fernyhough, Fradley, & Tuckey, 2001), language and cognitive development (Lemelin, Tarabulsy, & Provost, 2006; Pressman, Pipp-Siegel, Yoshinaga-Itano, & Deas, 1999), behavior (Bakermans-Kranenburg & Van IJzendoorn, 2006), and later adolescent adjustment (Stams, Juffer, & van IJzendoorn, 2002). Parental sensitivity is modifiable, as it can be improved with training (i.e., Bammens, Adkins, & Badger, 2015; Slade et al., 2005).

Parental sensitivity can be especially important for assisting young children with emotion co-regulation during stressful events, such as pediatric medical procedures. Children are particularly watchful for information from parents regarding situational safety during a traumatic event (Hornik & Gunnar, 1988; van der Kolk, 1987). Regarding pediatric injury, young children appear to react to their injury severity indirectly through their mother's (but not father's) psychological distress reactions (Haag & Landolt, 2017). Two studies have investigated maternal sensitivity during immunizations for infants and toddlers (Din, Pillai Riddell, & Gordner, 2009; Pillai Riddell et al., 2011). Higher maternal sensitivity (using an observational measure) was related with reduced pain-related distress behavior in the infants, however the effect appeared dependent on age such that maternal sensitivity was important for toddlers (1-year-old) but not infants (2–6-months-old) (Din et al., 2009; Pillai Riddell et al., 2011). The authors concluded this finding reflected the view that attachment relationship behavior is not reliably seen until 12 months of age (Ainsworth et al., 1978). Of note, paternal sensitivity was not assessed so we can only interpret the results as pertaining to the mother-child relationship. Furthermore, given the brevity of immunization procedures maternal sensitivity was actually assessed *following* the child's medical procedure. Therefore, we still do not know whether or how parental sensitivity is important for young child emotion regulation *during* a more extensive or invasive procedure.

Researchers have investigated parental verbal behavior during pediatric medical procedures, using a variant of the Child-Adult Medical Procedure Interaction Scale (CAMPIS; Blount et al., 1989). The

CAMPIS has been used to assess parent and child behavior during immunizations, bone marrow aspirations (BMAs), lumbar punctures (LP), anesthetic inductions, and intramuscular injections (Bearden, Feinstein, & Cohen, 2012; Blount et al., 1989; MacLaren Chorney et al., 2009). Using the CAMPIS, researchers can classify adult verbalizations as coping-promoting behavior (command to use coping strategy, humor, non-procedure-related talk to child) or distress-promoting behavior (reassurance, apology, giving control to the child, empathy, criticism). Similarly, researchers can classify child verbalizations as coping behavior (making a coping statement, non-procedure-related talk by the child, humor, deep breathing) or distress behavior (resistance, pain, fear, emotion, seeking information, seeking emotional support, crying, screaming). Frequency of each type of behavior is summed and divided by procedural time or total behaviors. It has been argued that the child's coping behavior is a coping response, while the child's distress behavior (and pain/fear scores) is a coping outcome to the stressful stimulus (Campbell, DiLorenzo, Atkinson, & Pillai Riddell, 2017).

While behavioral frequency measures such as the CAMPIS give information about discrete behaviors (parental sensitivity measures do not), there is concerns that it does not necessarily account for the individual needs of the child compared to parental sensitivity measures (Pillai Riddell & Racine, 2009). However, researchers can code multiple parental behaviors as coping-promoting on the CAMPIS, which allows parents to personalize how they demonstrate coping-promoting behavior. For example, a parent using non-procedural talk towards their child can choose any content that is interesting or specific to the child. Therefore, until parental sensitivity measures can be adapted to a range of procedural environments, as a proxy we suggest behavioral frequency measures give a rudimentary measure of parental sensitivity.

Behavioral frequency measures have demonstrated parental behavior is influential for a child's coping response and coping outcome (that is, distress behavior and reported pain intensity). Parental coping-promoting behavior has been positively related to child coping behavior and parental distress-promoting behavior has been positively related to child distress behavior prior to and during a procedure (Blount, Sturges, & Powers, 1990; Dahlquist et al., 2001; Dahlquist, Power, & Carlson, 1995; Dahlquist, Power, Cox, & Fernbach, 1994; Jacobsen et al., 1990; Lisi, Campbell, Pillai Riddell, Garfield, & Greenberg, 2013; MacLaren Chorney et al., 2009; Manimala, Blount, & Cohen, 2000; Sweet & McGrath, 1998). Less frequent child coping behavior and more frequent distress behavior has been associated to higher pain ratings (for a review, see MacLaren & Cohen, 2007). One laboratory study manipulated maternal behavior while their child underwent the cold pressor task (Chambers, Craig, & Bennett, 2002). The study found daughters reported the lowest pain when mothers were coached to use coping-promoting behavior, while daughters reported the

highest levels of pain when mothers were coached to use distress-promoting behavior. Daughters reported moderate levels of pain when mothers were not coached, in comparison to the other groups. This effect was not found for mother-son dyads. In sum, parental behavior during a medical procedure seems to be important for the child's coping response and coping outcome.

1.6.3 Parental psychological distress

Parents commonly experience acute psychological distress related to their child's injury or illness diagnosis and the resulting treatment. The range of parental psychological distress reactions that have been researched includes fear, general anxiety/depression, posttraumatic stress, and guilt. Parents self-report moderate to high levels of fear during infant immunizations (Bernard & Cohen, 2006), and young child intramuscular or portacatheter injections (Dahlquist & Pendley, 2005). Similar rates of fear across a range of procedures indicate the objective severity of the procedure or associated medical condition is not paramount for parents. In addition to fear, parents report other psychological distress symptoms when their child has a more severe medical condition. For example, parents have reported the presence of general anxiety/depression symptoms during pediatric cancer treatment (Best, Streisand, Catania, & Kazak, 2001). Moderate rates of clinically significant acute traumatic stress (27–50% prevalence) and strong feelings of guilt have also been reported by parents in the first month following pediatric burn injury (Bakker, Van Loey, Van der Heijden, & Van Son, 2012). A range of psychological distress symptoms are often present in parents of children undergoing medical treatment and may impact their parental sensitivity during this time.

Animal models have identified a pathway in which parents influence offspring distress. Rodent pups experienced social buffering (a diminished stress hormone release in the presence of a social partner) from their mother during stressful situations (Sullivan & Perry, 2015). However, the social buffering effect was overridden when the mother rodent experienced a fear response herself, resulting in a greater stress response in the pup (Sullivan, 2016).

Within humans, parental psychological distress has been linked to parent and child behavior during a medical procedure. Of note, parental fear has been primarily assessed in relation to parent and child procedural outcomes, despite the potentially high prevalence of other types of psychological distress. Prior to a procedure, parental fear has been positively associated with child pre-procedural distress behavior (for a review, see Racine, Pillai Riddell, Khan, et al., 2016) and procedural distress behavior (Dahlquist & Pendley, 2005; Jay, Ozolins, Elliott, & Caldwell, 1983). During a procedure, parental fear has been positively associated with increased child distress behavior (Bernard & Cohen, 2006). Parental fear also has been associated with less parental coping-promoting behavior (Bernard, 2001), or conversely, increased ignoring of the child (Bush &

Cockrell, 1987). Finally, parental fear and empathic concern during a procedure has been positively correlated with parent- and nurse-reports (but not child-reports) of child pain (Bernard & Cohen, 2006; Penner et al., 2008). Together, the research suggests direct and/or indirect effects of parental psychological distress on the child's coping outcomes. Further research is required to understand *how* parental psychological distress increases child distress behavior.

1.7 Outcomes of a distressing procedure

Medical conditions requiring hospitalization and the associated medical procedures may lead to ongoing psychosocial problems for the child. Following an injury or illness diagnosis, children often experience reduced health-related quality of life (HRQL) (McCarthy, MacKenzie, Durbin, & et al., 2006; R. L. Sheridan, Hinson, Liang, & et al., 2000), and increased emotional and behavioral problems (Liber, List, Van Loey, & Kef, 2006; Meyer, Robert, Murphy, & Blakeney, 2000). A significant minority of young children have been diagnosed with posttraumatic stress disorder (PTSD; 10–25%), separation anxiety (8–16%), oppositional defiant disorder (14–16%), depression (0–3%), attention-deficit/hyperactivity disorder (5–6%), and specific phobias (5–10%) in the first 6 months following injury (De Young, Kenardy, Cobham, & Kimble, 2012). Specific to medical procedural experiences, frequency of invasive procedures has been related to increased rates of PTSS in young children (Drake et al., 2006). Although these diagnoses tend to resolve with time, research in older children (6–16-years-old) has shown that without intervention some children (10%) remain affected at 2-years post-injury (Le Brocque, Hendrikz, & Kenardy, 2010).

Ongoing child psychosocial problems following medical treatment are due to many factors, including memories about the pain and trauma. The unique impact of procedural pain beyond injury- or illness-related pain has not been well established in the literature. A relationship between acute pain and PTSS following injury has been established in children (Hildenbrand, Marsac, Daly, Chute, & Kassam-Adams, 2016; Saxe, Stoddard, Hall, et al., 2005; Stoddard, Ronfeldt, et al., 2006). Pain memories have been implicated in linking acute pain to chronic pain and PTSS development (Holley, Wilson, Noel, & Palermo, 2016). Hyper-arousal and re-experiencing PTSS clusters likely increase attending to pain experiences (Liedl et al., 2010). Reducing the pain and distress associated with medical procedures should reduce the risk of developing traumatic memories and PTSS, thereby improving psychological outcomes for children following illness or injury. There are still large gaps in this research area, and further work could investigate the specific impact of procedural distress on long-term psychological problems in young children.

Parents can also experience ongoing psychological distress following their child's injury or illness diagnosis, and medical care. Studies have shown parents report similar rates of PTSD across child

medical conditions at 1 month following injury (11–22%), diabetes diagnosis (13–27%), or cancer diagnosis (44%) (De Young et al., 2014; Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003). Research on long-term parental psychological distress has primarily occurred in child burn injury recovery. At 3 months post-burn injury, a systematic review found 43–69% of parents reported significant anxiety symptoms, 27–81% of parents reported strong feelings of guilt, and 9–19% of parents reported PTSD (Bakker, Maertens, Van Son, & Van Loey, 2013). At 6 months after their child's burn injury, 5% of parents still reported a probable PTSD diagnosis (De Young et al., 2014). A closer examination of parental PTSS following their child's burn injury found 10–47% of parents reported clinically significant PTSS during the early months (Bakker et al., 2013; Hall et al., 2006) and 52% of parents reported a lifetime prevalence (Rizzone, Stoddard, Murphy, & Kruger, 1994). A significant proportion of parents experience ongoing symptoms of anxiety, guilt, and traumatic stress following a child's medical treatment, particularly for more severe conditions. Identification of risk factors for parental psychological distress can provide direction for early interventions.

Ongoing parental psychological distress is also likely due to traumatic memories, among other factors. Parental perceptions of their child's pain and threat to life have been implicated in PTSD development (Kassam-Adams, Fleisher, & Winston, 2009; Stoddard, Saxe, et al., 2006). For example, parents have reported witnessing their child's burns dressing changes as the "worst" part of the whole experience, a source of trauma as they often were required to physically restrain their child, and that it was horrifying to witness the physical injuries as well as their child's extreme fear (McGarry et al., 2015). Therefore, it is not surprising that parental psychological distress (i.e., general anxiety, depression, acute traumatic stress, guilt) during the treatment phase is predictive of longer-term psychological distress of general anxiety and/or PTSS (Best et al., 2001; De Young et al., 2014; Kazak & Barakat, 1997; Landolt et al., 2012). Reducing child distress behavior during medical treatment could improve long-term psychological adjustment for parents, in addition to improving the child's long-term psychological adjustment.

Parent and child psychopathology following injury or illness often coexist. Concordance of parent and child PTSS has been widely reported across pediatric medical conditions (De Young et al., 2014; Landolt et al., 2012). Caution should be used when interpreting parent-reported child PTSS, as research has shown parents with PTSS tend to over-report child PTSS, and parents without PTSS tend to under report child PTSS, compared to child self-reported PTSS (Kassam-Adams, Garcia-Espana, Miller, & Winston, 2006). However, a significant positive relationship remains between parent and child self-reported PTSS, after taking into account parents with more PTSS reporting more PTSS in their child (Egberts, van de Schoot, Geenen, & Van Loey, 2018). Therefore, there does seem be to a positive relationship between parent and child PTSS.

Potential modes of PTSS transmission between parent and child include common experiences, genetic vulnerabilities, and parenting behavior. Concurrent PTSS in the family can be explained through parents and children having a shared experience of and common reactions to the injury and medical treatment (Smith, Perrin, Yule, & Rabe-Hesketh, 2001). While this is likely true initially, longitudinal cross-lag analyses indicated parents play an influential role in the development and maintenance of child PTSS (De Young et al., 2014; Landolt et al., 2012). Concurrent PTSS in the family may also be due to genetic vulnerability (Drury et al., 2013; Saxe, Stoddard, Chawla, et al., 2005). Twin studies have shown moderate (approximately 30%) heritability for PTSS (Afifi, Asmundson, Taylor, & Jang, 2010), which indicates genetic vulnerability plays a part (although is not sufficient) in explaining the concordance. Concurrent PTSS in the family may also be due to changes in parenting behavior. Researchers have suggested parental psychological distress may reduce a parent's emotional availability to assist their child in co-regulating pain-related distress (Lieberman, 2004; Saxe, Stoddard, Chawla, et al., 2005; Stoddard, Saxe, et al., 2006). Parents who reported psychological symptoms were more likely to report frequent family conflict (Hall et al., 2006), and use avoidant, over-protecting or frightening behaviors (Scheeringa, Myers, Putnam, & Zeanah, 2015). Hall et al. (2006) hypothesized that increased family conflict was a result of anxious parents trying to avoid additional injuries through excessively restricting their child's activities. In contrast, Scheeringa et al. (2015) suggested child PTSS has greater influence than parental PTSS on parenting behavior. However, in both studies, it is difficult to make conclusions because these findings were based on self-reported rather than observed parenting behavior. There is a gap in understanding the nature of concurrent PTSS in the family following pediatric illness or injury diagnosis, although parenting behavior may play a role beyond shared experiences and genes.

1.8 Theories

For understanding parent and child procedural distress, the Integrative Model of Pediatric Medical Traumatic Stress provides a framework for the important phases of child and family adjustment throughout the child's medical journey (Price et al., 2016). The model emphasizes traumatic events can be experienced during the accident (Peri-Trauma Phase I), ongoing active medical treatment (Acute Medical Care Phase II), and once active medical treatment has ended (Ongoing Care or Discharge from Care Phase III) (Price et al., 2016). With regards to our time point of interest, young child procedural distress behavior during Phase II may: (1) be a product of the injury or illness diagnosis as a traumatic event itself (Phase I), (2) commence during acute medical care (Phase II), or (3) accumulate across Phase I and Phase II. While the authors hypothesized parenting behavior as the mechanism for PTSS transference, the model itself does not specify the influence of parenting behavior.

The relationship between parent and child behavior during a medical procedure is likely bidirectional in nature. Results from Blount et al. (1989), suggested distress is a circular relationship. Their published lag analyses can be summarized as three sequences: 1) Adult distress-promoting behaviors (excluding reassurance behavior) tended to precede child distress behavior; 2) Child distress behavior tended to precede adult reassurance behavior (but not other distress-promoting behaviors); and 3) Adult coping-promoting behavior tended to precede *and* follow child coping behaviors. Similarly, a systematic review of parent-child behavior during needle-related procedures concluded a bidirectional relationship is likely, however, noting parent behavior tended to precede child coping response (Campbell, DiLorenzo, et al., 2017). This comment aligns with the structure of the Child-Adult Medical Procedure Interaction Scale-Revised (CAMPIS-R) (Blount et al., 1997), which is designed to identify adult coping-promoting behaviors that encourage child coping responses (i.e., instructing the child to blow bubbles, followed by the child engaging in the instructed behavior). However, parents can also *reinforce* child coping responses with coping-promoting behaviors.

The influence of parental psychological distress during pediatric medical procedures has not been theoretically defined. Blount, Bunke, and Zaff (2000) hypothesized that parental "negative affect" impacts parental behavior and child behavior. However, the underpinning mechanism for these associations were not discussed. We now review alternative models from social learning and relational posttraumatic stress literature to conceptualize the role of parental psychological distress during medical procedures. Fisak Jr and Grills-Taquechel (2007) provided a review of learning theories applicable to the transmission of anxiety from the parent to the child, through parenting behavior. These theories are modelling, information transfer/instructional learning, and reinforcement of anxious behaviors. The authors proposed these theories of transmission likely worked in tandem. Examples are given of how these theories might be supported during a child's medical procedure.

1.8.1 Social learning theories

Modelling

Social learning theory (Bandura, 1986) and pathways of fear and anxiety development (Rachman, 1977) posit that children learn anxiety and avoidance behavior vicariously from their parents' modelling these behaviors. Anxiety, or fear, can be modelled through the expression of anxious thoughts and behavior in front of the child, displaying anxiety, and modelling avoidance behavior. Young children are not too young to learn and recall their parents' maladaptive coping strategies. Children as young as 10-months-old have been found to assess unfamiliar people or situations through parental nonverbal fear modelling (Feinman, 1992), and this information was retained over

time (Gerull & Rapee, 2002). In a medical procedure context, a parent can model anxiety and avoidance by not engaging with their child (i.e., not providing emotion co-regulation or coping-promoting behaviors).

Reinforcement of anxious behaviors

Rapee (2002) hypothesized that parents can support, assist and reward a child's anxiety and avoidance behaviors. In the face of a child showing distress, a parent can reinforce the distress by avoiding or removing their child from the anxiety-provoking situation to reduce distress, or allowing their child to avoid anxiety-provoking responsibilities (i.e., the child not walking to school because they are afraid to pass a house with a dog). Research findings have supported this model (Barrett, Fox, & Farrell, 2005; Barrett, Rapee, Dadds, & Ryan, 1996), showing that parents tended to discourage non-anxious/brave behavior and encourage avoidance and anxious behaviors in anxious children (Dadds, Marrett, & Rapee, 1996). In a medical procedure context, parents can reinforce their child's anxious behaviors when they *do not* praise their child for engaging in non-anxious/brave behavior during a medical procedure (e.g., "You stayed really still when they put the dressing on. Well done!"). This lack of coping-promoting behavior is similar to avoidance modelling, but in addition, parents can reinforce distress by excessively attending to (e.g., cuddling, soothing, reassuring) their child *when* the child displays anxious behavior.

Information transfer/instructional learning

Anxious parents can communicate (transfer) information to their child regarding safety and avoidance for potentially harmful situations, with increased frequency and/or excessive of the risk (Fisak Jr & Grills-Taquechel, 2007). Empirical support for this mode of transference is mixed (Lawson, Banerjee, & Field, 2007; Muris, Merckelbach, & Meesters, 2001), and further research is likely needed to test this mode separately from the other social learning models (Fisak Jr & Grills-Taquechel, 2007). According to cognition theories, communicating negative information is thought to increase the child's attention to threat stimuli (Hadwin, Garner, & Perez-Olivas, 2006), and research has shown that parents of anxious children encourage more avoidance behavior (Barrett et al., 1996). In a medical procedure context, a parent can communicate negative information to their child (e.g., "This is going to hurt a lot").

While these theories appear to have utility, it is important to take into account that they describe everyday parenting interactions for families where the parent has an established anxiety disorder. In comparison, a child's injury or illness diagnosis is an acute situation where the parent's and child's psychological distress are co-evolving in reaction to a specific event. We would expect co-evolving distress to be more dynamic in expression, as the parent and child individually and collectively

process their psychological distress in response to one or more potentially traumatic events. Experiencing co-occurring psychological distress may also disturb the child's ongoing social-emotional development. Furthermore, as psychological distress co-evolves, it is possible the child has not yet developed a protective response to the parent's expressed distress (or vice versa), compared to a more stable experience of a parent with an anxiety disorder. This susceptibility to parental psychological distress may be particularly prevalent during medical procedures, when emotion co-regulation is especially important for the child's experience of pain.

1.8.2 Relational PTSD theories

The PTSD literature also provide models to understand the parent-child relationship immediately following child injury or illness diagnosis, such as during medical treatment. Although PTSD theories are in essence applicable for families at least 1 month following a trauma, we suggest the theories are relevant for acute medical procedures. Considering parents commonly report PTSS in the days following their child's injury/illness diagnosis (i.e., Landolt et al., 2003), this acute symptomology is also likely to influence parental behavior in the days following the injury/illness diagnosis (including during the initial medical procedures). As PTSS include problems with regulating affect and being hyper-focused on threat, it makes sense that parents with PTSS could overreact to perceived threats with parenting behaviors that increase child distress. This effect on parental behavior may be even more pronounced during a child's medical treatment because it is related to, and would serve as a reminder of, the initial traumatic event (i.e., the child's injury or illness diagnosis).

Two models from the PTSD literature are relevant for understanding parent-child behavior during medical procedures. Scheeringa and Zeanah (2001) developed a model of relational PTSD wherein the PTSS of one family member affects PTSS of another family member (i.e., parent to child, and/or child to parent), such that there is a reciprocal or compound effect. Scheeringa and Zeanah suggested the PTSS was transferred through changes in behavior, specific to the present symptoms. Alisic, Boeije, Jongmans, and Kleber (2012) further developed Scheeringa and Zeanah's relational PTSD model to include a pathway in which parents without PTSS are able to engage in a sensitive parenting behavior (i.e., recognizing a child's needs, and acting on the need). These models are described in detail below, and applied to medical procedures.

Model of relational PTSD: The compound (mediation) effect

This model suggests one family member's (parent or child) PTSS exacerbates another family member's (parent or child) PTSS (Scheeringa & Zeanah, 2001). Each PTSD symptom cluster has corresponding negative behaviors: Avoidance symptoms are related to avoidance modelling behavior, hyper-arousal symptoms are related to overprotective behavior, and re-experiencing symptoms are related to frightening behavior. In a medical procedure context, a parent who has avoidance symptoms can model avoidance behavior by withdrawing from interacting with their child (and the medical procedure). Additionally, a parent who has re-experiencing symptoms, can increase the child's fear with warnings of pain (e.g., "This will hurt a lot like last time!"). Finally, a parent who has hyper-arousal symptoms may be over-reactive to the child during the procedure (i.e., excessively cuddle, soothe, reassure).

This model has been partially tested on young children in a mixed trauma sample (Scheeringa et al., 2015). The authors found self-reported parental behavior (escape/avoidance, sensitivity) at 11 months post-trauma positively predicted increased child PTSS at 36 months after the trauma. Both positive and negative self-reported parental behaviors have been associated with child PTSS previously (for a review, see Williamson et al., 2017), although the relationships are small. While the finding regarding escape/avoidance behaviors may have validity, it is counterintuitive to think that higher parental sensitivity is related to child PTSS. However, self-reported parental sensitivity does not seem to reflect observed parental sensitivity. Scheeringa et al. (2015) did not find an association between observed parental sensitivity at 11 months after the trauma and child PTSS at 36 months after the trauma. Again, considering parental sensitivity was first observed at 11 months after the trauma, the potentially important acute co-evolving reactions were not assessed, and parent-child interactions had likely stabilized by this time. Future work is still needed to assess the utility of this model by observing parent-child behavior during acute medical procedures.

Model of relational PTSD and recovery

Alisic et al. (2012) further developed Scheeringa and Zeanah's model to include a non-affected pathway. In essence, this qualitative study found parents reported that responsive parenting behavior was important following their child's injury. Similar to the definition of parental sensitivity, responsive parenting behavior was defined as being aware of and acting upon their child's needs. Furthermore, parents reported they felt their own psychological distress interfered with their capacity to engage in responsive parenting behavior. Alisic et al. proposed that responsive parenting behavior likely had an effect on their child's wellbeing. It must be noted that this model has not been tested as yet, as the model was developed from parents' self-report data, rather than observing parenting behavior. In a medical procedure context, a parent who is not experiencing PTSS, may be more likely to display responsive parenting behavior by being aware of and acting on

their child's need for emotional co-regulation (i.e., through coaching their child in distraction or deep breathing exercises), and avoiding distress-promoting behavior (i.e., excessive reassurance).

1.8.3 Development of a new model

With input from social learning and posttraumatic stress literature, and empirical support regarding parent-child behavior, we present our model of the relationship between parent and child distress within the context of a pediatric medical procedure in Figure 1.1. The mechanism underpinning the relationship between parental psychological distress and behavioral change is still not understood. Slade (2007) hypothesized that parents with low parental sensitivity are experiencing their own psychological distress. In line with this thinking, we propose a parent experiencing psychological distress after their child's injury or illness diagnosis can have difficulty mentalizing their child as a separate person. This difficulty can reduce the parent's ability to identify, prioritize, and appropriately respond to their child's need for emotional co-regulation during medical treatment.

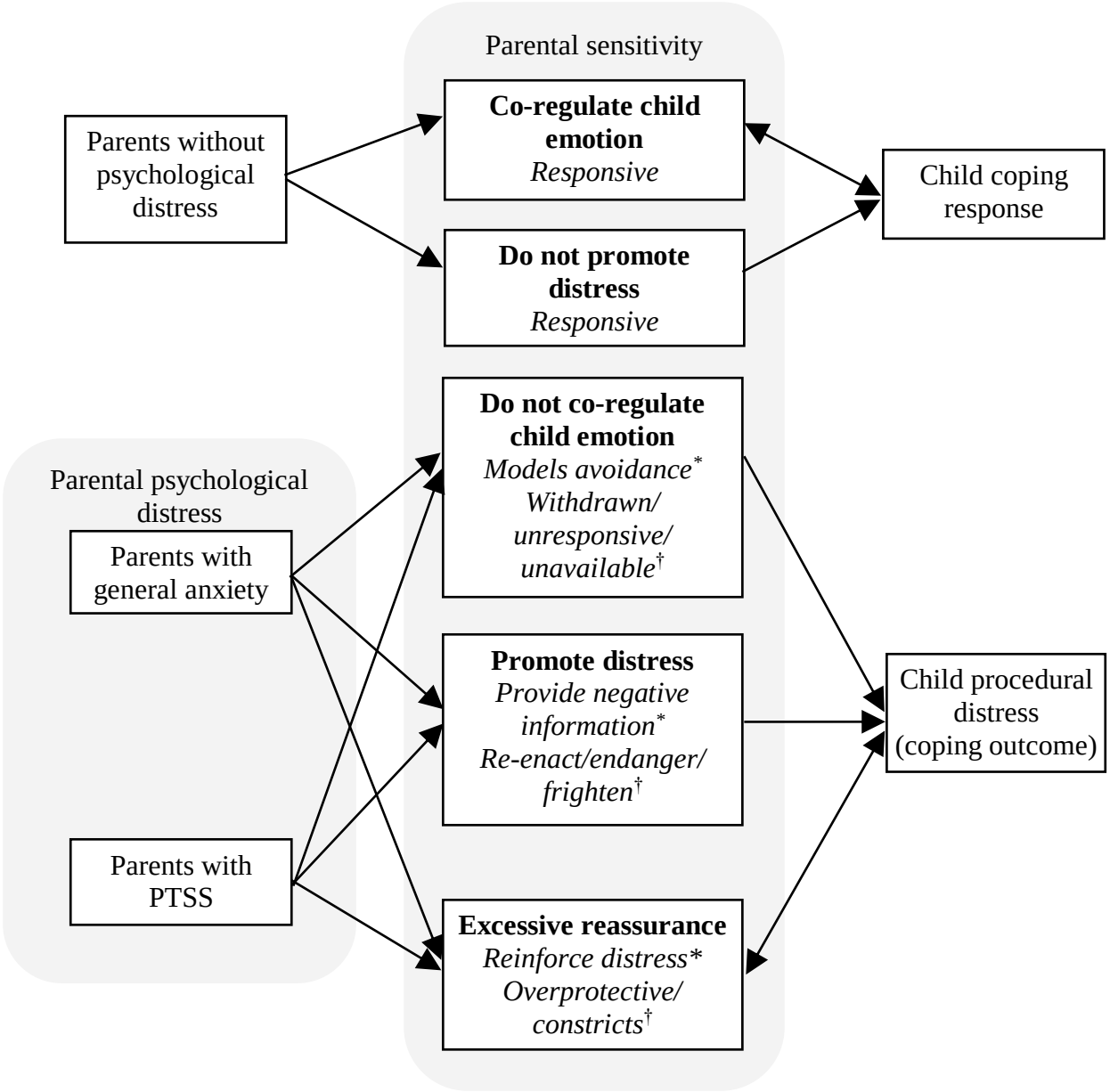


Figure 1.1 Model of parental psychological stress and behaviors as relating to child coping response and outcomes during pediatric medical procedures

*Parental behaviors previously theorized as pertaining to parental general anxiety.

†Parental behaviors previously theorized as pertaining to parental PTSS.

We acknowledge there is a presumption that a parent who does not experience psychological distress will be able to adequately engage in protective responsive parenting behavior (Alisic et al., 2012). While other factors, including individual personalities and experiences are associated with sensitive or responsive behavior (Katznelson, 2014), the purpose of this chapter is to understand the specific impact of parental psychological distress. We also understand that failure to engage in effective parenting behavior may be a consequence of reasons other than parental psychological distress, such as parental health status. Finally, taking into account the other previously identified risk factors of pediatric procedural distress (i.e., gender, previous medical experiences), we recognize that parenting behavior is not the only predictor of the child's coping response and coping outcome. We propose testing this model in a variety of pediatric medical procedures to assess applicability. Testing will also lead to further refinement of the model. For example, considering general anxiety and posttraumatic stress symptomologies differ, it would not be unreasonable to think they could differentially affect parenting behavior, despite the reviewed theoretical models proposing otherwise.

1.9 Assessment

For model testing, parent-child relationship measures of emotional co-regulation must be suitable for use in clinical environments. At present, measures are designed to identify parent and child behavior before or during a procedure (see Table 1.1). Sixteen measures were identified of which four were specifically related to pre-procedural distress (i.e., no painful stimulus was involved). As the measures were designed for different uses, there are strengths and weaknesses to each measure. In sum, further developments could be made to include the parent's and child's discrete behaviors, the parent's and child's nonverbal behaviors, and the child's coping response (positive behaviors). Coding discrete behaviors allow greater insight into potentially important specific responses. In contrast, some measures rate the overall frequency of composite behaviors (we term 'summary scoring'), for ease of use in clinical environments. However, it does not allow identification of important behaviors that may be specific to the medical procedure type. Additionally, coding child coping response behavior allows identification of emotion regulation. In a similar vein, coding adult behavior allows identification of emotion co-regulation attempts. While separate measures for adult and child behavior can potentially be used concurrently, a conjoint measure may make identifying emotion co-regulation simpler. Finally, coding of nonverbal behavior is important for expanding understanding of parent-child communication. Much communication is delivered nonverbally (Argyle, 1972), and parents and young children would also (partly) communicate nonverbally, particularly as young children have limited language abilities. Coding discrete behaviors, child

coping responses, adult behaviors, and nonverbal communication in future measures should enhance identification of emotion co-regulation throughout a medical procedure.

Table 1.1 Review of observational measures used in a medical setting

Reference	Measure	Child age[a]	Type of procedure	Detail[b]	Mode	Child scoring[c]	Adult scoring[c]
Visintainer and Wolfer (1975)	Manifest Upset and Cooperation Scales	3–12	Venipuncture, anesthetic induction	Summary (two 5-point scales)	Live	Distress behavior (V, NV) Cooperative behavior (V, NV)	None
E. R. Katz, Kellerman, and Siegel (1980)	Procedure Behavior Rating Scale (PBRS)	0–17	Oncology (BMA)	Discrete (25 behaviors)	Live	Distress behavior (V, NV)	None
Jay et al. (1983)	Observation Scale of Behavioral Distress (OSBD)	2–20	Oncology (BMA)	Discrete (11 behaviors plus intensity on 4-point scales)	Video	Distress behavior (V, NV)	None
Jay and Elliott (1990)	Parent Behavior Scale (PBS)	3–12	Oncology (BMA or LP)	Summary (8 items, presence or absence)	Live	None	Physical support behavior (NV) Verbal support behavior (V) Instructions to child behavior (V) Breathing exercises behavior (NV) Imagery exercises behavior (NV)

Reference	Measure	Child age[a]	Type of procedure	Detail[b]	Mode	Child scoring[c]	Adult scoring[c]
							Information to child behavior (V) Talk to child behavior (V) Distress behavior (V, NV)
Bush, Melamed, Sheras, and Greenbaum (1986)	Dyadic Pre-Stressor Interaction Scale (DPIS)	4–10	Pre-procedure	Discrete (10 behaviors)	Video	Attachment behavior (V, NV) Distress behavior (V, NV) Exploration behavior (V, NV) Prosocial behavior (V, NV)	Ignoring behavior (NV) Reassurance behavior (V, NV) Distraction behavior (V, NV) Restraint behavior (V, NV) Agitation behavior (V, NV) Informing behavior (V, NV)
Hubert, Jay, Saltoun, and Hayes (1988)	Behavioral Approach-Avoidance and Distress Scale (BAADS)	3–11	Oncology (BMA)	Summary (5 items, each scored with two 5-point scales)	Live	Distress behavior (V, NV) Coping style (approach or avoidance) (V, NV)	None
Kain et al. (1995)	Yale Preoperative Anxiety Scale (YPAS)	2–6	Anesthetic induction	Summary (categorical)	Video or Live	Activity (NV) Vocalizations (V, NV)	None

Reference	Measure	Child age[a]	Type of procedure	Detail[b]	Mode	Child scoring[c]	Adult scoring[c]
						Emotional expressivity (NV) State of apparent arousal (NV) Use of parents (V, NV)	
Kain et al. (1997)	Modified Yale Preoperative Anxiety Scale (m-YPAS)	2–12	Pre-anesthetic induction and anesthetic induction	Summary (categorical)	Live	Activity (NV) Vocalizations (V, NV) Emotional expressivity (NV) State of apparent arousal (NV) Use of parents (V, NV)	None
Blount et al. (1989)	Child-Adult Medical Procedure Interaction Scale (CAMPIS)	5–13	Oncology (BMA/LP)	Discrete (35 behaviors)	Video	All behavior (V)	All behavior (V)

Reference	Measure	Child age[a]	Type of procedure	Detail[b]	Mode	Child scoring[c]	Adult scoring[c]
Blount et al. (1997)	Child-Adult Medical Procedure Interaction Scale - Revised (CAMPIS-R)	4–7	Immunization	Discrete (35 behaviors)	Video	Coping behavior (V) Distress behavior (V) Neutral behavior (V)	Coping-promoting behavior (V) Distress-promoting behavior (V) Neutral behavior (V)
Kain, Mayes, Wang, Caramico, and Hofstadter (1998)	Induction Compliance Checklist	2–8	Gaseous induction	Summary (11 items, present or absent)	Live	Distress behavior (V, NV)	None
Blount, Bunke, Cohen, and Forbes (2001)	Child-Adult Medical Procedure Interaction Scale – Short Form (CAMPIS-SF)	3–7	Immunization	Summary (5-point Likert scale)	Live or video	Coping behavior (V, NV) Distress behavior (V, NV)	Coping-promoting behavior (V, NV) Distress-promoting behavior (V)
Tucker, Slifer, and	Brief Behavioral Distress Scale (BBDS)	2–10	Implanted port access, venipuncture,	Summary	Video	Distress behavior (V, NV)	None

Reference	Measure	Child age[a]	Type of procedure	Detail[b]	Mode	Child scoring[c]	Adult scoring[c]
Dahlquist (2001)			IM, subcutaneous injection, transfusion			Active coping response behavior (V, NV)	
Cohen, Bernard, McClelland, and MacLaren (2005)	Measure of Adult and Infant Soothing and Distress (MAISD)	0–1	Immunization	Discrete (15 behaviors)	Video	Coping behavior (V, NV) Distress behavior (V, NV)	Coping-promoting behavior (V, NV) Distress-promoting behavior (V)
Sadhasivam et al. (2010)	Perioperative Adult Child Behavior Interaction Scale (PACBIS)	3–12	Pre-anesthetic induction, anesthetic induction, and IV catheter removal	Summary	Live	Coping behavior (V, NV) Distress behavior (V, NV)	Positive behavior (V, NV) Negative behavior (V, NV)
Beringer, Greenwood, and	Pediatric Anesthesia Behavior (PAB)	2–12	Interveneous induction	Summary	Live	Preoperative anxiety (V, NV)	None

Reference	Measure	Child age[a]	Type of procedure	Detail[b]	Mode	Child scoring[c]	Adult scoring[c]
Kilpatrick (2014)							

Notes. BMA=Bone Marrow aspiration, LP=lumbar puncture, IM=intramuscular injection

[a]Years are inclusive, i.e., 3–5 indicates children 3.00–5.99 years of age.

[b]Level of detail of measure classified as summary (summary scores or scale items) or complex (individual behaviors coded).

[c]Coded behavior has been identified as verbal (V) or nonverbal (NV).

The existing observational measures have child age restrictions, such that children 0–4 years of age cannot be scored on the same measure. There are challenges for creating a valid measure across an age group that differs extensively on developmental milestones. For example, infant coping (0–2-years-old) has been characterized by coding nonverbal behavior, while child coping (2–17-years-old) has been characterized by coding verbal behavior (Cohen et al., 2005). However, for medical procedures specific to young children, one common measure that scores verbal and nonverbal behavior would bridge the age groups. Research studies often have specific child age inclusion criteria that are constrained by the validity of the chosen observational measure. Therefore, it is currently challenging to have a good understanding of procedural experiences of young children specifically.

Existing observational measures have not been validated across a wide range of procedures. See Table 1.2 for a review of the characteristics of researched samples. Twenty-five studies were identified, of which there were 18 immunization/venipuncture samples. Although research is needed for minimizing distress during pediatric immunizations/venipunctures, these findings may not be generalizable to other procedural experiences. For example, immunizations are quick procedures, while cancer and burns treatments are longer, more painful, reoccur, and related with more serious prognoses. However, oncology and burn patients also have vastly different experiences. Cancer treatment represents a serious life-threatening illness that has ongoing repercussions for the child and the family. Alternatively, a burn injury represents a definitive and potentially traumatic accident, and the recovery involves managing ongoing pain, grafting, wound care procedures, itch, and adhering to scar management. Parents of a child with a cancer diagnosis may feel more grief, while parents of a child with a burn injury may feel more guilt. Therefore, findings regarding parent and child experiences and behaviors during a particular medical procedure may not apply to another medical procedure.

Table 1.2 Review of research samples that have investigated parent behaviors during pediatric medical procedures

Medical Procedure	Study	Country	Sample Size (*N*)	Age in Years
Oncology (BMA/LP/IM)	Blount et al. (1989, 1990, 1991)	USA	23	5-13
	Penner et al. (2008)	USA	41	3-12
	Dahlquist et al. (1994)	USA	66	2-17
	Dahlquist et al. (1995)	USA	51	5-13
	Dahlquist et al. (2001)	USA	45	5-15
Immunization/	Blount et al. (1992)	USA	60	3-7
Venipuncture	Cohen et al. (1997)	USA	92	4-6
	Cohen et al. (2000)	USA	55	4-6
	Cohen et al. (2002)	USA	61	3-7
	Cohen et al. (2005)	USA	62	0-1
	Blount et al. (1997)	USA	77	4-7
	Blount et al. (2001)	USA	60	3-7
	Bearden et al. (2012); Cohen et al. (2015)	USA	90	4-6
	Frank et al. (1995)	USA	77	4-7
	Gonzalez et al. (1989)	USA	47	1-8
	Gonzalez et al. (1993)	USA	43	3-7
	Jacobsen et al. (1990)	USA	70	3-10
	Sweet et al. (1998)	Canada	60	0-1
	Lisi et al. (2013)	Canada	760	0
	Manimala et al. (2000)	USA	82	3-6

Medical Procedure	Study	Country	Sample Size (*N*)	Age in Years
	Manne et al. (1992, 1994)	USA	43	3-9
	Spagrud et al. (2008)	Canada	55	3-18
	Taylor et al. (2011)	Australia	66	3-12
IV Insertion	McCarthy et al. (2010)	USA	542	4-10
Anesthetic Induction	Chorney et al. (2009)	USA	293	2-10

Notes. BMA=Bone Marrow aspiration, LP=lumbar puncture, IM=intramuscular injection

Another concern is that studies have not been conducted across a wide range of cultural contexts. Parent-child attachment styles differ across cultures (Keller, Voelker, & Yovsi, 2005; Keller et al., 2004; Russell, Hart, Robinson, & Olsen, 2003), and as such, families and children may demonstrate different behaviors during medical procedures, due to different ethnic backgrounds, as well as across different cultural contexts. With the majority of the research conducted in the USA, recommendations about optimal parent and child behavior during a medical procedure should not be generalized to other ethnicities and cultural contexts without testing. The field should be mindful to include diverse samples to be able to expand generalizability. Further development of observational assessment measures is required before specific parenting interventions for reducing young child procedural distress can be developed and tested.

1.10 Non-pharmacological interventions for procedural distress

Understanding the existing range of non-pharmacological interventions available for children during medical procedures is important before designing interventions aimed at modifying parenting behavior. Hospitals utilize a range of non-pharmacological interventions designed to minimize and/or reduce child procedural distress. One extensively researched area is the use of distraction. Distraction is thought to shift the child's attention from pain signals, and as attention is considered to be a limited resource, the experience of pain and fear is thus reduced (Kleiber & McCarthy, 2006; Lambert, 1999). Recent reviews regarding children and needle-related procedural pain (Uman et al., 2013), and other medical procedures (Koller & Goldman, 2012) give comprehensive summaries of the distraction literature. In essence, distraction can be coded as active (giving the child a task) or passive (redirecting the child's attention) (Kleiber & Harper, 1999).

Active distraction interventions include electronic interactive devices, virtual reality, and controlled breathing. Research on active distraction has generally found positive effects for reducing fear and maintaining this reduction over multiple procedures (Koller & Goldman, 2012, for a review). The Ditto™ electronic distraction device (Diversionary Therapy Technologies, Queensland, Australia) found significant reductions in pain, fear, and had a reduced wound healing time for children (4–12-years-old) with a burn injury (N. J. Brown, Kimble, Rodger, Ware, & Cuttle, 2014). Virtual reality also has merit for reducing pain, fear, and distress behavior, and increasing positive affect, particularly when tailored to the procedure type (i.e., a snow scene for children with burn injuries; Sharar et al., 2007). The positive effects of virtual reality have been successfully maintained over time, although immersive (i.e., using a headset) virtual reality, and older children (10–14-years-old) have shown stronger positive effects (Koller & Goldman, 2012). Controlled breathing (via bubble blowing, breathing exercises, party blowers, and pin wheels) is also associated with increased

relaxation, and reduced pain and distress behavior (Koller & Goldman, 2012). Importantly, research on the effects of active distraction have mainly been explored in minor needle-related procedures (Koller & Goldman, 2012), and may be less effective in more painful procedures. Developmental appropriateness for young children must also be considered, as young children often have not yet developed the cognitive capacity to engage with these platforms.

Passive distraction includes audio (music) and audio-visual (television) stimuli. Audio distraction research has found mixed effects for increasing relaxation, and decreasing pain, fear, and distress (Koller & Goldman, 2012). The authors suggested that treatment type and length, child's age, and intensity of pain can negate effects of audio distraction. In essence, auditory interventions may not be salient enough for reducing pain in more invasive pediatric medical procedures. Comparatively, research on audio-visual distraction has found mixed effects for pain and distress reduction, across a variety of procedures (Koller & Goldman, 2012). Some researchers have argued that active distraction is reliant on a child's willingness and cognitive capacity to engage during a painful event, while passive distraction only needs a child's attention (Bellieni et al., 2006; Berenson, Wiemann, & Rickert, 1998; MacLaren & Cohen, 2005). Given older and less distressed children seem more able to use active distraction (Chambers, Taddio, Uman, & McMurtry, 2009), passive distraction is potentially more effective in younger or more distressed cohorts. However, audio-visual distraction is still not consistently effective for child coping behavior during more invasive procedures (Landolt, Marti, Widmer, & Meuli, 2002). For young children, age appropriate passive and active distraction should be offered concurrently to maximize effectiveness.

Non-pharmacological interventions appear to be more effective with adult coaching (Cohen, Bernard, Greco, & McClellan, 2002). Adult coaches have included dedicated specialists, trained medical staff, and trained parents. Hospitals can employ dedicated specialists such as medical hypnotists, child life therapists, and clown doctors. Medical hypnosis on children (3-years-old and older) reduced pain and distress behavior, equal to or exceeding the effect of other distraction interventions (for reviews, see Accardi & Milling, 2009; Uman et al., 2013). However, the authors caution that these results should be considered in light of relatively small sample sizes and methodological weaknesses (Accardi & Milling, 2009). There is a paucity of research on the effectiveness of other specialist groups, although they are clinically accepted as beneficial for child outcomes. Child life therapists use age-appropriate procedural preparation and play therapy (Brewer, Gleditsch, Syblik, Tietjens, & Vacik, 2006), while clown doctors use humor and distraction (Vagnoli, Caprilli, Robiglio, & Messeri, 2005) to reduce child distress. However, employing people for these fulltime positions is costly when upskilling existing medical staff may be just as effective. Nurses trained in coaching children in coping behavior have been effective in

reducing child distress (Cohen, Blount, & Panopoulos, 1997; Cohen et al., 2006). As the procedural expert, nurses are uniquely equipped to guide the child with coping strategies throughout the procedure. In comparison, Young (2005) commented that parents are ideal coaches as they know their child's specific interests but do not always know how to help their child during medical procedures. Therefore, training parents to coach the child can be effective for the immediate and all future medical procedures; however, it does require considering and addressing the parent's own psychological state.

1.10.1 Parenting interventions for procedural distress

Understanding the onset and impact of pediatric procedural distress is important for considering intervention approaches. Price et al. (2016) recommends that interventions be designed to *change* the child's subjective experience in Phase I (Peri-trauma), *prevent* child PTSS in Phase II (Acute Medical Care), and *reduce* child PTSS in Phase III (Ongoing Care or Discharge from Care). Therefore, preventing procedural distress has the potential to reduce prevalence of ongoing distress (in the parent and the child) long term. Research on child coaching alone (i.e., training the child but not the parents or nurses) is not always adequate for reducing child distress behavior (Cohen et al., 2002). Previous parenting interventions have attempted to address parental influence on child behavior during medical procedures. A systematic review of interventions for child immunization, found evidence for parent-led distraction/coaching to reduce distress behavior, though not pain severity (Chambers et al., 2009). This finding led the authors to hypothesize that parental fear or lack of adherence to new behaviors may have impaired coaching behavior. The efficacy of specific interventions will now be reviewed.

The efficacy of brief video/interactive computer program interventions to alter parenting behavior for reducing young child distress and/or pain during medical procedures has been tested with mixed results. Brief videos/interactive computer programs (5–10 minutes duration) are compatible for use within a busy clinical environment. These studies have tested brief video interventions for parents of children undergoing immunization (Cohen et al., 2015; Pillai Riddell et al., 2017) and intravenous insertion procedures (Kleiber, Craft-Rosenberg, & Harper, 2001). All studies found significant improvements in parental behavior. Regarding child distress behavior, studies by Cohen et al. and Kleiber et al. failed to find a significant difference, however Pillai Riddell et al. found a significant decrease in child distress behavior at 1 and 2 minutes post-procedure (but not at time of insertion or 3 minutes post-procedure). This finding indicates parental behavior training did not reduce the child's distress response to the procedure itself, but parents helped co-regulate their child's emotion more quickly after the procedure. Additionally, the non-significant results by Cohen et al. and Kleiber et al. may be explained by the measures not assessing time points within the

procedure, as Pillai Riddell et al. did, therefore hiding the effect within the total behavioral score. Regarding pain, there was no difference in self-reported scores in Cohen et al. and Kleiber et al. (Pillai Riddell et al. did not collect self-reported pain data).

A more extensive parenting behavior intervention has also been developed and tested for parent and child outcomes. Parents of children (3–9-years-old) undergoing oncology venipuncture procedures were provided with a combination of preparation and support (Manne et al., 1990). Prior to the procedure, parents watched a video before practicing behaviors through role playing with a psychologist. Throughout the procedure, the psychologist was present to prompt parents on specific behaviors. The intervention significantly reduced parental fear, child distress behavior, and child pain (parent-reported but not child self-reported). This result indicates additional preparation and support altered the parent's interpretation of their child's pain, possibly through a reduction in parental fear. The involvement of a psychologist is akin to employing dedicated specialists, which can be expensive for the hospital as well as time-consuming for the parents.

Other researchers have attempted to address parental anxiety rather than child distress behavior or pain during pediatric procedures. Jay and Elliott (1990) focused on reducing parental psychological distress through stress-inoculation training. Parents of children (3–12-years-old) undergoing oncology procedures (bone marrow aspiration/lumbar puncture) were given a 15-minute video, followed by a 15-minute therapy session, then a 15-minute relaxation audio recording. The intervention taught common emotional reactions, misconceptions, positive coping verbal and nonverbal behaviors, the use of self-statements, and incorporated a relaxation session. The program significantly reduced parental self-reported anxiety, but not parent distress-promoting behavior or parent physiological stress. Differences in child distress behavior and pain were not analyzed, although if parenting behavior did not change it is likely the child's behavior did not change either.

Another intervention designed to reduce parental and child preoperative fear was the ADVANCE brief video program, for families of children (2–10-years-old) undergoing anesthetic induction (Kain et al., 2007). In the days leading up to the procedure, parents watched a training video at least twice and were given information pamphlets regarding preparing their child, managing their own and their child's fear, and how to distract their child, and staff encouraged preparatory role playing at home. During the induction, additional distraction toys were available for the child, and staff prompted parents to utilize distraction strategies. The ADVANCE program successfully reduced child behavioral fear, parental fear, and improved physical recovery outcomes post-operatively (i.e., lower incidents of emergence delirium, reduced analgesic consumption, quicker discharge). Although not assessing child distress behavior directly, the findings indicate that it is useful to provide parents with strategies to manage their own psychological distress, when asking the parent

to coach their child in coping strategies. Of note, this intervention required extensive preparation by the parents, and medical staff to be trained and willing to implement the intervention. When designing an intervention, staff burden should be taken into consideration to ensure the program is feasible beyond efficacy trials (Glasgow, Lichtenstein, & Marcus, 2003). Parental anxiety appears to be an important aspect of parental interventions that has not been fully explored to date.

Conflicting recommendations have been made regarding designing parent training interventions. Recently, researchers have recommended parents are explicitly discouraged from using distress-promoting behavior (during needle-related procedures) (Campbell, DiLorenzo, et al., 2017; Campbell, Pillai Riddell, Cribbie, Garfield, & Greenberg, 2017; Pillai Riddell et al., 2017). This recommendation stems from findings that suggest reducing parental distress-promoting behavior is more important for child coping outcomes than increasing parental coping-promoting behavior (Campbell, Pillai Riddell, et al., 2017). A similar effect has been found regarding parental appraisals during parent-child conversations about the trauma, and child PTSS: Negative appraisals were more important than positive appraisals for limiting child PTSS (Hiller et al., 2017). However, Blount et al. (1989), proposed that parental distress-promoting behavior would reduce as a natural consequence of increasing parental coping-promoting behavior (during oncology bone marrow aspiration/lumbar puncture procedures). Explicitly discouraging certain behaviors could have unintended consequences, particularly during more invasive and potentially distressing pediatric medical procedures. For example, explicit discouragement may be considered fear-based messaging (i.e., "if you do this, your child will experience more pain"), which might actually increase parental psychological distress during a heightened setting such as an invasive medical procedure. Soames Job (1988) posited that emotionally framing messages using fear are not as helpful as positive reinforcement for health promotion campaigns. Parental interventions may be more effective if the message is delivered through positive reinforcement rather than explicit discouragement.

Timing of intervention delivery should also be considered for maximizing effectiveness. For reoccurring procedures, we expect training parents prior to the first procedure will be the most effective for minimizing child distress. If a parental intervention is only delivered after a distressing procedure/s, the parents and the child will have preexisting negative expectations regarding future procedures, particularly for the reoccurring procedures. Previous experience will also likely provide the parents and the child with a set of previously chosen behaviors to repeat during future procedures. Decisions made at the first medical procedure regarding behavior will likely inform subsequent procedure behavior (i.e., Song, Qu, Blumm, & Barabási, 2010). Therefore it could be argued that in order to change the trajectory of physical and psychological recovery, the optimal time to intervene is as early as possible during the child's medical treatment.

Parental interventions may have positive effects beyond the family, such as increasing medical staff wellbeing. Research for pediatric leukemia procedural pain (Kazak et al., 1996) has shown that a combined family-centered psychological-pharmacologic intervention decreased medical staff depersonalization over time. Kazak et al. extrapolated that increased resources for pain management may lead to medical staff maintaining patient connectedness and empathy during painful procedures. The potentially negative impact of medical staff routinely performing invasive procedures on young children must be considered. Interventions designed to reduce child distress behavior can also benefit medical staff wellbeing, as well as improve workplace outcomes.

1.11 Future directions

Throughout the paper, we have identified four broad recommendations for future directions in the pediatric medical trauma research field. Firstly, current assessment tools need to be expanded to improve availability and generalizability. Specifically, assessment tools should include discrete and nonverbal behaviors of the parent and child, and the positive behaviors (coping response) as well as distress behaviors (coping outcome). Assessment tools should be modified and validated for specific age groups, types of procedures, and in different cultural contexts. Secondly, we have presented a conceptual model of the relationship between parent and child distress during medical procedures. This model requires testing, and may lead to refinement. Another recommendation is that long-term recovery outcomes following procedural distress specifically should be explored. These outcomes may range from length of time required for wound healing, to child and parental posttraumatic stress symptoms, and the child's quality of life and behavioral problems in the following months. Finally, parenting behavior interventions should provide parents with strategies to manage their own psychological distress, as well as focus on teaching coping-promoting behaviors, to more effectively minimize pediatric procedural distress. The timing of the intervention should be as early as possible during medical care for greater effect.

1.12 Conclusions

Following a potentially traumatic event such as a child's injury or illness diagnosis, parents can have differing responses during their child's painful medical procedures. As a consequence of their own psychological distress, parenting behavior may also change during this time, to impact child adjustment. A distressing pediatric medical procedure likely has negative long-term consequences for the child and the parent, although existing procedural pain research has not specifically investigated this relationship.

Further research in this area is important for three key stakeholders. Firstly, researchers should consider the systemic impact of the family during pediatric medical procedures, the relationship

between procedural pain and long-term traumatic stress, and consider theory testing and intervention. Secondly, medical professionals should be aware of acute and cumulative effects of medical trauma on parents, and the impact on how a parent presents during their child's medical procedure. Psychosocial training for medical professionals regarding addressing parent psychological distress, coaching parent behavior, and modelling correct behavior during a pediatric medical procedure will likely have significant psychological advantages for the parent, child, and all medical professionals involved. Finally, parents should be aware of their influence during their child's medical procedure, and be informed of strategies for managing their own psychological distress, and their child's distress behavior. This information can help all parents during contact with pediatric hospital and health services.

Chapter 2. Overview of study methodology

2.1 Preamble

Chapter 1 provided a review of the literature in terms of parental emotional and behavioral influence on pediatric procedural distress and recovery following an injury or illness diagnosis. Based on the literature, a theoretical model was presented that depicts the relationship between parental psychological distress and child procedural distress, mediated through parenting behavior. However, to date no study has tested this model. Furthermore, no study has investigated the consequences of a distressing procedure in terms of child physical recovery, and parent and child psychological recovery.

The remainder of the thesis will focus on studying these relationships within a pediatric burn injury sample. Pediatric burn injuries and the subsequent wound care procedures can be distressing for the child and the parent. Therefore, recruiting families of a child with a burn injury provides a sample of parents who are potentially experiencing psychological distress from the injury, which might affect their child during burn wound care. This thesis used an observational cohort study with prospective longitudinal design approach. Self-report measures were collected prior to the observation, and medical data were obtained. In order to assess parent-child behavior during burn wound care, 1) an observational measure must be developed and validated (Chapter 3). This measure will allow 2) the mediation model to be tested in a sample of young children with burn injuries and their parents (Chapter 4). Subsequently, the consequences of a distressing procedure can be assessed in terms of 3) burn re-epithelialization (Chapter 5), and; 4) long-term child and parent psychosocial outcomes (Chapter 6).

2.2 Introduction

This chapter provides a detailed description of the study methodology utilized to collect data that informed Chapters 3–6 of this thesis. This chapter will clarify the setting, participants, and procedures utilized to guide the reader. This chapter presents an overview of the sample size and attrition, however, it does not present any findings as this is the focus on the subsequent chapters.

2.3 Setting

Families were recruited and observed at their presentation for first dressing change at the Pegg Leditschke Children's Burns Centre (PLCBC), Queensland Children's Hospital, Brisbane, Australia. The PLCBC is a tertiary-level pediatric burns referral center for a catchment of approximately 5 million people and treats approximately 1,000 new burns per year. The participants in this study were recruited through the PLCBC outpatients' clinic. A multidisciplinary team works in the outpatients' clinic, including nurses, doctors (consultants, residents, and registrars), occupational therapists, physiotherapists, social workers, students, researchers, and the occasional clown doctor. Typically, the clinic runs on weekdays from 7:30 a.m. until 10:30 a.m., and 5–25 patients are seen each day. Patients are taken to 1 of 5 treatment rooms based on order of arrival, and clinical staff move between the rooms. There is no psychological or child life specialist involvement in the clinic. A number of research studies were recruiting at the time of data collection for the data presented in this thesis. All families are initially screened for agreeing to research involvement, before being individually approached for a specific research project.

2.4 Participants

Parents of children were eligible for recruitment if 1) the child was aged 1–6-years-old; 2) parents had consented to researchers approaching them during clinic; 3) the dressing had not been changed previously; 4) the burn was sustained less than 8 days previously, and; 5) the burn was deeper than a superficial classification. Families were excluded from participating if 1) the child had a developmental disorder (e.g., autistic spectrum disorder), or; 2) the child had a comorbid head injury (Glasgow Coma Scale < 12); 3) the child's injury was from suspected abuse or neglect; 4) the primary caregiver was not present; 5) the parent's English ability was insufficient for completing questionnaires and verbal coding, or; 6) the child's wound care was conducted under general anesthetic in the operating theatre. All children received oral premedication (i.e., including oxycodone, paracetamol, ibuprofen, midazolam, and/or fentanyl), and the observed procedure included dressing removal, wound debridement and washing. The participant flow is outlined in Figure 2.1.

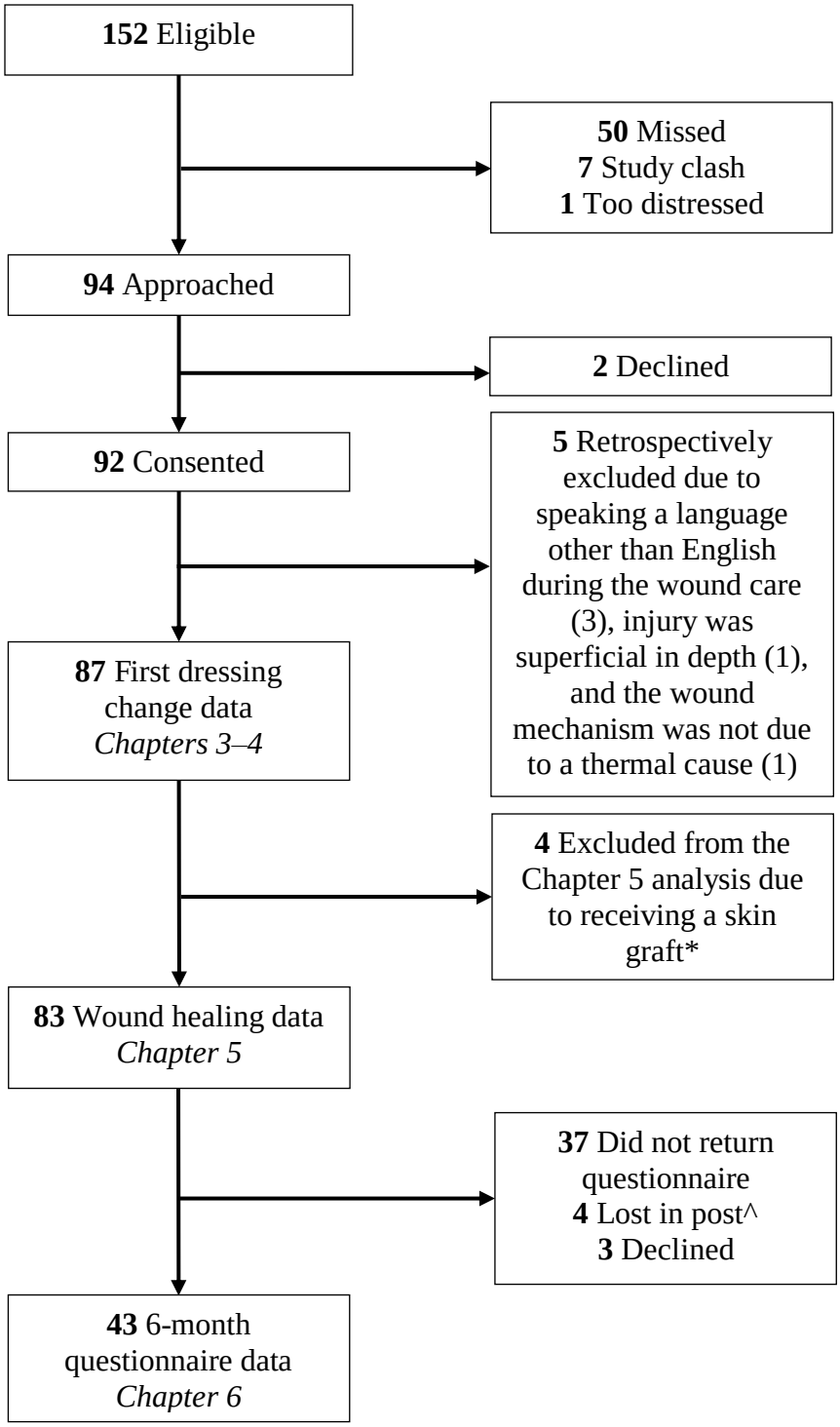


Figure 2.1 Flow chart of data utilized for this thesis and relevant chapters indicated

*Parents of children with a skin graft were invited to complete the 6-month questionnaire (presented in Chapter 6).

^During follow up reminder contact, four parents reported completing and returning the questionnaire through the post, however, these questionnaires were never received.

While Chapter 1 defined young children as under 5-years-old, the remainder of the thesis adapts the definition of young children as 1–6-years-old. This was done during study design for a number of reasons. A lower limit of 1-year-old was chosen because 1) children under the age of 1-year-old rarely sustain burn injuries as they are not yet developmentally mobile; and 2) parent-reported psychological measures (i.e., Child Behavior Check List; Young Child Posttraumatic Checklist) are not validated for children under 1-year-old. The low potential participant pool and the difficulty in assessing psychological distress in children under 1-year-old led to this exclusion. An upper limit of 6-years-old was decided because although children aged 5–6-years-old are able to self-report pain (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001), they are not validated to self-report psychological distress (i.e., the Child Trauma Screen Questionnaire is for children 7-years and older, Kenardy, Spence, & Macleod, 2006). Despite the large developmental differences between 1–6-year-old children, it was concluded that the availability of parent-reported measures indicated it was possible to focus on this particular age range of children.

2.5 Measures

Table 2.1 provides an overview of the measures utilized in this study. Measure details and psychometric properties are discussed in the relevant chapters.

Table 2.1 Summary of measures collected for thesis

Measure	First dressing change	6-month questionnaire
Parent-report:		
Demographics	✓	
Behavioral inhibition	✓	
Fear	✓	
State pain	✓	
Parent self-report:		
Global Guilt Scale	✓	
Primary care PTSD screen	✓	
Patient Health Questionnaire-4	✓	
Fear	✓	
Observer-report:		
CAMPIS-R; CAMPIS-SF; B-CAMPIS	✓	
Nurse-report:		
Face, legs, arms, consolability, cry	✓	
Parent-report:		
Young child PTSD checklist		✓
Child behavior checklist		✓
State pain		✓
Pediatric Quality of Life Inventory		✓
Parent self-report:		
Posttraumatic Diagnostic Scale		✓
Parenting Stress Index		✓
Post-trauma Inventory of Parenting Style		✓
Medical data		
Days until re-epithelialization		✓
Administered medication	✓	
Need for grafting/scar management		✓

PTSD=Posttraumatic Stress Disorder; CAMPIS-R=Child-Adult Medical Procedure Interaction Scale-Revised; CAMPIS-SF=Child-Adult Medical Procedure Interaction Scale-Short Form; B-CAMPIS=Burns-Child-Adult Medical Procedure Interaction Scale.

The first focus of the first dressing change data collection, was to develop and validate an observational assessment tool (the B-CAMPIS, Chapter 3). Observer-reported data and parent- and nurse-reported child pain and fear were utilized at this time-point. The second focus of the first dressing change data was to assess the influence of parental acute psychological distress on parent-child behavior during the dressing change (Chapter 4). Parent self-reported measures, as well as the observer-reported B-CAMPIS data were used for this analysis. Data collected at the first dressing change were then tested in relation to wound healing (Chapter 5). First dressing change and medical data were accessed for this analysis. Finally, 6-month data were collected and analyzed (Chapter 6). Parent-reported child psychological functioning, and parent self-reported psychological functioning measures were assessed to report prevalence of impaired functioning. Additionally, first dressing change data were utilized to predict child and parent psychological functioning at 6 months post-injury.

2.6 Procedure

Parents of children admitted to the PLCBC were recruited consecutively between September 2015 and June 2016. A researcher (E.A.B) screened potential families for eligibility and approached on arrival to the outpatient's clinic. After written consent was obtained, the parent completed the demographic and mental health questionnaires in the waiting room. A researcher observed the dressing change for verbal (audio recorded) and nonverbal behavior (coded live), from the time the nurse began to remove the dressing to approximately 2 minutes after the wound was debrided and washed. Afterwards, parents and nurses retrospectively completed measures of child fear and pain. At 6 months after the burn, parents were mailed a follow-up questionnaire. Parents were reminded up to three times via telephone to complete and return the questionnaires. At this time, medical data were obtained from hospital records.

Chapter 3. Development and validity of the Burns-Child-Adult Medical Procedure Interaction Scale (B-CAMPIS) for young children

Brown, E. A., De Young, A. C., Kimble, R., & Kenardy, J. (2018). Development and validity of the Burns-Child-Adult Medical Procedure Interaction Scale (B-CAMPIS) for young children. *Burns, 45*(1):76-87. doi: 10.1016/j.burns.2018.08.027

3.1 Contribution to authorship

The design of this study was shared between myself (80%) and my supervisors. I collected the data myself (100%) and am responsible for the statistical analyses (100%) and interpretation of the results (100%). I am responsible for writing the paper (100%), on which my supervisors provided detailed feedback.

3.2 Preamble

As identified in Chapter 1, currently no suitable observational measure exists for use with parents and young children undergoing pediatric burns wound care. This chapter aims to empirically address this gap. Specifically, the Burns-Child-Adult Medical Procedure Interaction Scale (B-CAMPIS) was developed which included non-verbal scoring and burns-related behaviors. Inter-coder reliability was attained, and the B-CAMPIS was validated against two other observational tools designed to parent-child procedural interactions (CAMPIS-SF and CAMPIS-R), as well as parent- and nurse-reports of child pain, fear, and behavioral distress. Development of the B-CAMPIS allows research to investigate parent-young child interactions during burn wound care. This chapter comprises of a paper that has been published in *Burns*, with minor modifications.

3.3 Introduction

Young children (under 6-years-old) are at risk of increased pain-related distress during medical procedures because they have an underdeveloped cognitive capacity and thus difficulty rationalizing procedural pain as necessary, helpful, and temporary (McGrath & Frager, 1996; Young, 2005). Research on child pain-related distress during medical procedures has predominantly been conducted on children undergoing oncology (Blount et al., 1997), perioperative anesthetic induction (Caldwell-Andrews, Blount, Mayes, & Kain, 2005), and immunization procedures (Cohen et al., 2005). The majority of children who are hospitalized due to injury (e.g., drowning, poisoning, falls, and burns), are under 5-years-old (Australian Institute of Health and Welfare, 2014). Burn injury rates commence as children become mobile at 9-months-old, peaks for children aged 1–2-years-old, declines for children aged 3–6-years-old, and remains relatively low after this age (Stockton et al., 2015). Monitoring child behavior during all types of medical procedures is valuable, because behavior is often indicative of pain and distress (Blount, Piira, & Cohen, 2003). Medical procedures relating to injuries might be particularly distressing for children, as it can serve as a reminder of the injury itself and has been implicated in posttraumatic stress development (Hildenbrand et al., 2016). Considering the prevalence of injuries in young children, there is a unique need for an observational tool to assess young child procedural distress, and for it to be validated for use in a variety of injury-related medical procedures.

One important yet understudied cohort is families undergoing pediatric burn wound care. Burn wound care (debridement and dressing change) is often painful and distressing, and is repeated until re-epithelialization (wound healing). Understanding the young child's experience during burn wound care is particularly relevant because the procedure can be especially painful due to physiological changes that can interfere with the provision of adequate pharmacological pain management (Sharar et al., 2008). Also, burn injuries are related to more frequent posttraumatic stress symptoms compared to other injuries (Le Brocque et al., 2010). Posttraumatic stress symptomology (avoidance, hyper-arousal, intrusive thoughts, negative mood) can be especially prevalent and affect a child's behavior during burn wound care. Observational research in young child burn wound care is important because increased pain and fear during pediatric burn wound care has been associated with delayed re-epithelialization (N. J. Brown, Kimble, Rodger, Ware, & Cuttle, 2014; K. Miller et al., 2011) as well as ongoing psychological distress (Saxe, Stoddard, Hall, et al., 2005).

In addition to pharmacological intervention, non-pharmacological pain management interventions are available for school-aged children undergoing burn wound care. Children 4 years and older are

commonly offered the Ditto™ device (an electronic preparation and distraction device, and is available through Diversionary Therapy Technologies, Queensland, Australia) (N. J. Brown, Kimble, Rodger, Ware, & Cuttle, 2014). Other work has recognized the benefits of virtual reality, which is suitable for children 6-years-old and older (Sharar et al., 2007). The availability of these interventions rely on uptake by the particular burns center. Burns centers may also employ psychologists and child life therapists to assist with procedural distress. However, there are currently no non-pharmacological pain management interventions available for young children, despite their high risk for experiencing procedural distress. Understanding a young child's experience during burn wound care is necessary to inform interventions for improving care.

Parenting behavior is a key factor in child coping and distress behaviors during medical procedures (Chapter 1, published as E. A. Brown et al., 2018b). A medical procedure can be highly distressing for young children (Kain et al., 1996), and children are particularly attentive to their parents' reactions during a stressful event (Hornik & Gunnar, 1988; van der Kolk, 1987). A parent engaging in emotion co-regulation (appropriately assisting the child to regulate their emotional responses) (Camras et al., 1996; Cassidy, 1994; Gottman et al., 1997) will likely result in a calmer procedure. However, parenting behavior during a child's burn wound care may be impacted by the additional stress of witnessing their child in pain, the shock of seeing the wound, guilt about the injury, ongoing worry about the injury severity, need for grafting, and the potential for scarring (McGarry et al., 2014; McGarry et al., 2015; Morley, Holman, & Murray, 2017).

Key parent-child behaviors have been previously identified and validated. Child distress behaviors include crying, screaming, flailing, requiring restraint, resisting, verbalizations of fear and pain, negative emotion, seeking emotional support and information (Blount et al., 2001; Blount et al., 1997). Behaviors that indicate child coping include making a coping statement, non-procedural talk, deep breathing, playing, and looking at their parent (Blount et al., 2001; Blount et al., 1997; Cohen et al., 2005). For parents, distress-promoting behaviors include criticism, reassurance, giving the child control, apologizing, and empathy (Blount et al., 1997; Caldwell-Andrews et al., 2005). Finally, parent coping-promoting behaviors include humor, non-procedural talk, command to engage in a coping strategy, playing, offering a soothing item, and demonstrating what to do (Blount et al., 2001; Blount et al., 1997; Cohen et al., 2005). A common observational measure used for interpreting parent and child (4-13-years-old) behavior during medical procedures is the CAMPIS-R (Blount et al., 1997; Blount et al., 1989). The CAMPIS-R identifies 35 verbal behaviors that are grouped into three child behavior categories ("coping", "neutral", and "distress"), as well as three adult behavior categories ("coping-promoting", "neutral", and "distress-promoting"). The

CAMPIS-R was initially developed using a sample of children undergoing bone marrow aspiration/lumbar puncture procedures as part of cancer treatment (Blount et al., 1989).

To date, no studies have observed parent-child interactions during burn wound care. A variety of observational instruments have been utilized to assess child distress behavior during burn wound care. Studies investigating child distress behavior during burn wound care have used the Observational Scale of Behavioral Distress (OSBD) measure (Foertsch, O'hara, Stoddard, & Kealey, 1996; Landolt, Marti, et al., 2002; Sil, Dahlquist, & Burns, 2013), Children's Hospital of Eastern Ontario Pain Scale (CHEOPS) (Hernandez-Reif et al., 2001), COMFORT behavior scale (COMFORT-B) (van Dijk et al., 2000), Pain Observation Scale for Young Children (POCIS) (de Jong et al., 2012), or the Face, Legs, Arms, Cry, Consolability (FLACC) measure (K. Miller et al., 2011; Moore, Bennett, Dietrich, & Wells, 2015). The OSBD and CHEOPS require videoing, while the FLACC, POCIS, and COMFORT-B can be coded live. Five of the studies assessed young children with mean ages between 2–4-years-old (de Jong et al., 2012; Hernandez-Reif et al., 2001; Moore et al., 2015; Sil et al., 2013; van Dijk et al., 2000), and three studies assessed older children with mean ages between 6–8-years-old (Foertsch et al., 1996; Landolt, Marti, et al., 2002; K. Miller et al., 2011). These measures do not code child coping behaviors or adult behaviors, which are important for identifying the parent's influence (i.e., emotion co-regulation) on their child's behavior (Chapter 1, published as E. A. Brown et al., 2018b). In comparison, the CAMPIS-R does code child coping behavior and adult behavior, however it is not able to be used with preverbal children. Further work is required to create a valid and reliable measure for specifically assessing parent-young child interactions during burn wound care.

In order to expand the CAMPIS-R to be relevant for use with families of young children undergoing burn wound care, the measure must include child and parent nonverbal behavior. Adding nonverbal coding to the measure is important because children 1–3-years-old primarily communicate emotion through nonverbal behavior (Ensor, Spencer, & Hughes, 2011; Vallotton, 2008). With regards to developing a measure that assesses all young children (1–6-years-old), it is expected that children aged 1-year-old to show the lowest rates of verbal behavior, children aged 2-years-old to show an increase in verbal behavior, and comparatively children aged 3–6-years-old to show the highest rates of verbal behavior. Only coding verbal behavior would miss the majority of interactions between young children and their parents. There are also likely a lot of nonverbal behavior by parents that are not currently captured, nor important parenting behaviors specific to burn wound care. Considering the unique burden of witnessing burn wound care (McGarry et al., 2014; McGarry et al., 2015), it is possible there are other parenting behaviors that are unique to burn

wound care that are related to child coping or distress. It is expected that including these additional behaviors will improve the measure's validity.

A new observational measure should show convergent and discriminant validity with alternative measures, regarding the parent, child, and associations between parent and child behaviors. Previous research has established varying degrees of convergent (not discriminant) validity in parent-child observational measures. Relevant measures include the CAMPIS-SF (Blount et al., 2001), Measure of Adult and Infant Soothing and Distress (MAISD) (Cohen et al., 2005), and Perioperative-CAMPIS (P-CAMPIS) (Caldwell-Andrews et al., 2005). A summary of which behaviors were validated in these measures are reported in Table 3.1. To more effectively validate our new measure, we aim to analyze the convergent and discriminant validity of parental behavior and child behavior (coping and distress) with a range of alternative measures.

Table 3.1 Summary of validated behaviors in parent-child observational measures

	CAMPIS-SF	P-CAMPIS	MAISD
Parental behavior	✓	×	×
Child coping behavior	✓	×	×
Child distress behavior	✓	✓	✓

Beyond testing for convergent validity, it is recommended that other types of validity be evaluated (MacLaren Chorney, McMurtry, Chambers, & Bakeman, 2015). For the current study, we will modify an existing measure (the CAMPIS-R) to a specific population (i.e., burn wound care for young children), and as such incremental validity (the value of the new measure compared to the original measure in assessing a construct) should also be demonstrated. Therefore, in developing a new measure, the purposes of this paper are to 1) report inter-coder reliability; 2) confirm the nature of additionally identified behaviors in relation to existing validated behaviors (used in other instruments); 3) assess behavioral differences in children of different ages, and; 4) test whether the modified measure is valid for assessing parent and child behavior in the burn wound care context, using convergent, discriminant, and incremental tests of validity.

3.4 Materials and methods

3.4.1 Participants

Parents of children aged 1–6-years-old who had sustained an unintentional burn injury, were recruited at the child's first burn wound care appointment, at the PLCBC, Queensland Children's Hospital, Brisbane, Australia, during September 2015 to July 2016. A pilot sample was recruited to refine the measure and reach inter-coder reliability before the main sample was recruited to assess validity. To test for coder drift, inter-coder reliability was also assessed in 20% of the main sample. All recruited children were given pharmacological pain relief prior to the dressing removal. Consistent with outpatient clinical practice, sedative medication was not administered to any child in this study. Exclusion criteria specified 1) if the dressing had been changed prior to this appointment; 2) if the number of days since the injury exceeded 7 days (to exclude delayed presentations); 3) if the child had a diagnosed developmental disorder, or; 4) comorbid head injury; 5) the injury was suspected abuse or neglect; 6) the primary caregiver was absent, or; 7) the family spoke insufficient English for questionnaire completion and verbal behavior coding. The University of Queensland Human Research Ethics (approval number 2015000623) and the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (approval number HREC/15/QRCH/27) approved this study. Participating parents provided written informed consent. Participating children were not required to give assent as all children were under the age of 7-years-old.

3.4.2 Procedure

Potential participants were approached upon arrival to the center. Prior to the dressing removal and debridement, parents were asked to report on demographic information, including items regarding ages, ethnicity, gender, education, and annual family income. The nonverbal behavior of the child and parent was coded before, during and after dressing removal and debridement. Given the small examination rooms often held all attending family members (i.e., both parent/s, grandparent/s, and sibling/s) and at least one nurse, the raters stood in close proximity whilst not intruding or potentially interfering with the procedure, in an attempt to observe the same behaviors while under instruction to ignore the other rater's coding behavior. Audio recordings were made concurrently, and subsequently transcribed for coding verbal behavior. Consistent with previous research (Cohen et al., 2005), coding initiated when the nurse began to remove the dressing, and completed 2 minutes after debridement (the washing and cleaning of the wound), unless the child left the room earlier. Following coding, the coder asked the parent to report the child's procedural pain and fear retrospectively, and the nurse reported the child's pain-related distress behavior.

3.4.3 Measures

Development of the Burns-CAMPIS (B-CAMPIS)

The B-CAMPIS was developed under the recently published guidelines for pediatric behavioral coding (MacLaren Chorney et al., 2015). A pool of potential behaviors was identified through a literature search, consulting health professionals, and direct observations. Firstly, verbal behaviors were identified from the CAMPIS-R measure (Blount et al., 1997), and nonverbal behaviors were identified from the MAISD (Cohen et al., 2005), CAMPIS-SF (Blount et al., 2001), and P-CAMPIS (Caldwell-Andrews et al., 2005) measures. Additionally, nonverbal behaviors specific to burn wound care were identified through consultations with a range of pediatric burns healthcare professionals (doctors, nurses, occupational therapists, social workers, psychologists, and physiotherapists) and the researcher observed a large number of burn wound care procedures prior to commencing the study. Identified additional nonverbal child behaviors included gaze to injury, using the Ditto™ device, watching television, and aggressive behavior (i.e., intentionally kicking or hitting someone). Using the Ditto™ device and watching television were considered distinct behaviors as they are forms of active and passive distraction (respectively). Identified additional nonverbal parent behaviors included crying and unengaged distress. A parent demonstrated unengaged distress when they did not initiate or respond to their child because they were distressed themselves. All behaviors were operationalized in terms of behavior examples and how to score each behavior.

Scoring. The frequency of each discrete behavior was calculated. The frequency of continuous behavior (i.e., playing) was coded in 10-second time blocks, similar to previous methods (Blount et al., 1997; Cohen et al., 2005). For example, a child who looked at the television screen for 1 second (discrete behavior), looked away for 2 seconds, then reengaged with the screen for 2 seconds (discrete behavior), was represented by a frequency score of 2. In comparison, a child who looked at the television screen for 11 seconds (continuous behavior) is also represented by a frequency score of 2. The frequencies of behaviors relating to each CAMPIS-R category (child coping, child distress, parent coping-promoting, parent distress-promoting) were summed then divided by the procedure duration to give a rate of behavior, as recommended previously (MacLaren Chorney et al., 2015).

Coder training and inter-coder reliability. Two coders were trained on the first version of the B-CAMPIS to establish reliability. A pilot sample of parents of 15 children 1–6-years-old presenting for burn dressing changes was recruited for reliability training and refinement of the B-CAMPIS measure. Children were predominantly male (*n*=11, 73%), with a mean age of 2.45-years-old

(*SD*=1.53). Data from the pilot study was not included in the main study sample. For coding verbal behavior, the coders reviewed the CAMPIS-R manual. The coders discussed reasons for coding discrepancies after coding each transcript for verbal behavior. Inter-coder reliability was assessed using intra-class correlations (ICCs) rather than Kappa because the data is ordinal in nature (i.e., 2 instances of reassurance is larger than 1 instance) and Kappa analyses are appropriate for data that is nominal in nature (Hallgren, 2012). Additionally, ICCs consider the magnitude rather than absolute disagreement, and this is valuable because of the difficulty in attaining absolute reliability when scoring *in vivo* data that is expected to occur at a low frequency (i.e., Rater #1 recording 2 instances of a behavior, and Rater #2 observing 1 instance) (Hallgren, 2012). After coding the verbal behavior of 10 families, ICCs reached excellent agreement for parent (ICCs .98-1.00) and child (ICCs .99-1.00) behaviors. ICCs were assessed according to Cicchetti (1994).

For coding nonverbal behavior, the coders reviewed the operationalized definitions and examples. The coders discussed reasons for coding discrepancies after coding each dressing removal and debridement for nonverbal behavior. Closer examination of inter-coder reliability data from the pilot study revealed certain behavior codes could be collapsed. For example, it was common to observe a parent demonstrating to their young child how to play with a toy. Because of how young the children were, this behavior could be easily interpreted as 'engaging in play' 'action example' and/or 'offering a soothing item'. These codes were merged into the single adult nonverbal coping-promoting behavior, entitled 'distract'. After coding nonverbal behavior of 15 families, ICCs reached good to excellent agreement for parent behaviors (ICCs .74–.90), and fair to excellent agreement for child behaviors (ICCs .52–1.00). Familiarization of the codes, recruiting and training for nonverbal coding during outpatient clinics, and verbal coding from transcripts was completed in approximately 5 days.

Although agreement was lower than preferred, this rate is similar to agreement rates on previous nonverbal behavioral measures (Cohen et al., 2005). Lower reliability rates have been associated with low base behavior frequencies (Spitznagel & Helzer, 1985), which was the case in the pilot sample. Greater variability is also to be expected when coding behavior live because there is increased potential to overlook behaviors. Only child nonverbal behavior 'requiring restraint' failed to attain at least good agreement in the pilot sample (i.e., an ICC of .60). In addition, a number of parent behaviors (criticism, apology, empathy, command to engage in a coping strategy, crying, unengaged distress) and child behaviors (scream, seeking emotional support, verbal fear, verbal emotion, information seeking, making a coping statement, non-procedural talk, humor, breathing, reading, aggression) were not observed in the pilot sample. These behaviors will be tested for inter-coder reliability in the main sample.

Subsequently identified parent behavior. When reviewing transcripts from the main sample, there were three additional verbal adult behaviors that were not present in the pilot sample, but seemed to represent important information parents communicated to their child during burn wound care. Additional verbal parenting behaviors included 'prompting disclosure of pain', 'threat to remove coping strategy', and 'negative evaluation of the wound'. Parents prompted the child to disclose pain, such as "That looks painful, does it hurt a lot?" Parents also threatened the child to remove a coping strategy (i.e., a distracting toy) in an attempt to control behavior, such as "I'll take away the iPad if you can't play quietly". Finally, burn wounds are uniquely graphic compared to other pediatric medical procedures, and parents reacted with negative evaluations of the wound such as "That looks disgusting!". These behaviors were added to the B-CAMPIS.

Structure of the B-CAMPIS. The B-CAMPIS was developed as an expansion of the CAMPIS-R. Therefore, the CAMPIS-R child and parent coping and distress behavioral categories were retained. The exception is the 'neutral' child and parent behavioral categories. As the coders were required to code non-verbal behavior *in vivo* as an acknowledgement of the sensitivity of the situation for parents and staff, the decision was made to eliminate neutral behavior scoring as a means to reduce coding burden and potentially increase reliability of coping and distress codes.

Validity measures for child behavior

Parent-reported child pain. Parents rated their child's procedural pain score using the Numerical Pain Rating Scale (Downie et al., 1978). The 11-point scale was used to identify the parent's report of the "worst pain your child has experienced during this medical treatment". The left anchor was titled *no pain*, and the right anchor was titled *worst imaginable pain*. Parent-reported procedural pain scales have been positively correlated with child self-reported pain (Chambers, Reid, Craig, McGrath, & Finley, 1998).

Parent-reported child fear. Parents reported their child's procedural fear using the Visual Analogue Scale-Anxiety (VAS-A) (Choiniere, Melzack, Rondeau, Girard, & Paquin, 1989). The VAS-A is a single item measure of fear consisting of a continuous line 10cm in length. The left anchor is *no anxiety or fear*, and the right anchor is *worst possible anxiety or fear*. The VAS-A was developed to be a self-report tool, but has been also used as a proxy-report tool for pediatric medical procedures (Bringuier et al., 2009). Parent-reported child fear has been validated against child self-reported fear (Bringuier et al., 2009).

Child behavior. The child behavior scales in the CAMPIS-SF (Blount et al., 2001) were used to assess construct validity for child behavior in the B-CAMPIS. An observer gives overall scores for child coping behavior and child distress behavior on two validated 5-point Likert scales (*none/one*

to *maximum/continuous*), based on the child's verbal and nonverbal behaviors. The CAMPIS-SF has good reliability (κs>0.88), and validity against other child distress measures (*rs*>.39, *ps*<.001). For the current study, good to excellent reliability was established (Coping ICC=.63, Distress ICC=.82).

Nurse-reported child pain-related distress behavior. A nurse rated the child's procedural pain-related distress behavior using the FLACC (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997). The FLACC is an additive observational measure with five subscales. Each subscale (Faces, Legs, Arms, Consolability, Cry) can score 0–2, for a total score of 0–10 (0 represents no distress, 10 represents the highest distress possible). The FLACC has excellent responsiveness, reliability, and validity (von Baeyer & Spagrud, 2007), and is recommended for nurse-reported young child distress across a range of hospital departments (Manworren & Hynan, 2003).

Validity measures for parent behavior

Parenting behavior. The CAMPIS-SF (Blount et al., 2001) and the CAMPIS-R (Blount et al., 1997) were used to validate parenting behavior. As for the child, the CAMPIS-SF has two 5-point Likert scales to give overall scores for parental coping-promoting behavior and distress-promoting behavior. The CAMPIS-SF has good reliability (κs>0.74) and validity for parental coping-promoting and distress-promoting behavior against the CAMPIS-R parenting behavior categories (*r*s>.75) (Blount et al., 2001). For the current study, good to excellent inter-coder reliability was obtained for the CAMPIS-SF (Coping-promoting ICC=.81, Distress-promoting ICC=.70). The CAMPIS-R consists of three coping-promoting behaviors (nonprocedural talk to the child, humor to the child, commands to use coping strategy), and five distress-promoting behaviors (verbal reassurance, apologies, empathy, giving control to the child, criticism). The CAMPIS-R has strong reliability (κs>0.78) and validity for parental coping-promoting and distress-promoting behavior against child distress behaviors (*rs*>.33) (Blount et al., 1997). For the current study, excellent inter-coder reliability was obtained for the CAMPIS-R (Coping-promoting ICCs>.99, Distress-promoting ICCs>.99).

3.4.4 Statistical Analyses

Descriptive statistics were presented using medians and inter-quartile ranges (IQR) for non-normally distributed data. Categorical variables were presented using frequencies and percentages. Inter-coder reliability of the pilot and final versions of the B-CAMPIS were assessed between the two coders using ICC analyses in SPSS 24 for Windows. All ICCs were calculated using ordinal measure, two-way mixed effect, absolute agreement, and averages (Hallgren, 2012). ICCs were rated in accordance with Cicchetti's values of poor (0.00–0.39), fair (0.40–0.59), good (0.60–0.79)

and excellent (0.80–1.00) (Cicchetti, 1994). Due to the non-normality of the data, Spearman's Rho correlation analyses were used to assess the relationship between raw frequencies of additional identified behaviors with raw frequencies of previously validated behaviors.

The data retained non-normality when the rate of behavioral frequency per minute was calculated. Therefore, the effect of child's age group on rates of displayed behavior was analyzed using Kruskal-Wallis tests. Based on the increase in language acquisition from 2-years-old (Fletcher-Campbell, Soler, & Reid, 2009), we divided the cohort into three groups of children aged 1-, 2-, and 3–6-years-old. Significant findings were followed up using the one-tailed Jonckheere-Terpstra test to test for potential trends in rates of behavior by age. In addition to the *J*-test statistic, we reported the *z* score (a *z* score of >1.65 indicates a significant trend, and a positive *z* score indicates the rate of behavior is increasing as the child's age increases), and the effect size of the trend, *r*.

Analyses were performed to test convergent, discriminant, and incremental validity. Convergent validity was tested using Spearman's Rho correlations for the B-CAMPIS rate scores against the CAMPIS-SF scales and the CAMPIS-R rate scores. Incremental validity was examined using univariate linear regression analyses. This served to compare the variance accounted for by the B-CAMPIS child categories to the CAMPIS-R child categories in predicting parent-reported child procedural pain and fear, and nurse-reported child pain-related distress behavior. The proportion of variance in the outcome explained by each model (B-CAMPIS and CAMPIS-R) was presented using the R^2 value. All analyses were performed using SPSS 24 for Windows (IBM Corp, 2016) and *p*-values with $p<.05$ were considered statistically significant.

3.5 Results

Three previously reported child coping behaviors (reading, humor by child, nodding) remained unobserved in the final sample, and were therefore omitted from the final B-CAMPIS measure. These behaviors were likely unobserved because of the young age of the children. Child B-CAMPIS codes not previously found in the CAMPIS-R include gaze to injury, using the Ditto™ device, watching television, and aggression. Parent B-CAMPIS codes not previously found in the CAMPIS-R include prompt disclosure of pain, negative evaluation of the wound, threat to remove coping strategy, parent cry, and unengaged distress. These behavior codes were hypothesized to relate to the indicated categories, as reported in Table 3.2. See Appendix B for the nonverbal coding sheet for the final version of the B-CAMPIS.

Table 3.2 B-CAMPIS behaviors for child and parent

	Child		Parent	
	Coping	Distress	Coping- promoting	Distress-promoting
Verbal behavior	Making a coping statement	Cry	Humor directed to the child	Criticism
	Non-procedure related talk	Scream	Non-procedure related talk to	Verbal reassurance
	by child	Verbal resistance	child	Giving child control
	Audible deep breathing	Seek emotional support	Command child to engage in a	Apologizing
		Verbal fear	coping strategy	Empathizing
		Verbal pain		*Prompt disclosure of pain*
		Verbal emotion		*Negative evaluation of the wound*
		Information seeking		*Threat to remove coping strategy*
Nonverbal behavior	Play	Flail	Point to distract	Reassuring contact[#]
	Point to décor	Requires restraint	Distract (play, action example,	*Parent Cry*
	Self-soothing	*Aggression*	offer)	*Unengaged distress*
	Gaze to parent			
	Gaze to injury			
	Using the Ditto™ device			
	Watch television			

[#]Classified as distress-promoting in the P-CAMPIS. Italicized behaviors were not included in previous observational measures.

3.5.1 Demographics

Of the 92 families recruited, three families were excluded due to speaking a language other than English during the dressing removal and debridement, one child's injury was superficial in depth, and for one child the wound mechanism was an infection rather than due to a thermal cause. The remaining sample consisted of 87 parent-child dyads. See

Table 3.3 for the sample characteristics.

Table 3.3 Sample characteristics

Sample Characteristics (*N*=87)	*n* (%)
Child	
Age, mean±SD (range), years	2.40±1.12, (1.04–6.94)
1-year-old	35 (40)
2-years-old	22 (25)
3-years-old	8 (9)
4-years-old	5 (6)
5-years-old	11 (13)
6-years-old	6 (7)
Sex	
Male	50 (57)
Female	37 (43)
Ethnicity, *n*=76	
Anglo/European	60 (69)
Pacific Islander	8 (9)
Asian	5 (6)
African	2 (2)
Aboriginal/Torres Strait Islander	1 (1)
Not stated	11 (13)
Parent	
Sex	
Mothers	73 (84)
Fathers	14 (16)
Age, mean±SD (range), years, *n*=75	32.37±5.31 (21–43)
Education	

Sample Characteristics (*N*=87)	*n* (%)
High school education or less	21 (22)
Technical training	20 (27)
University degree	32 (44)
Not stated	14 (16)
Annual family income, $AUD	
Less than $40,000	9 (10)
$40,000-80,000	19 (22)
$80,000-120,000	20 (23)
More than $120,000	21 (24)
Not stated	18 (21)
Injury	
Burn depth	
Superficial-partial	63 (72)
Deep-partial	21 (24)
Full-thickness	3 (4)
%TBSA, mean±SD (range)	1.90±2.10 (0.50–12.00)
Injury mechanism	
Scald	42 (48)
Contact	42 (48)
Friction	2 (3)
Radiant Heat (sunburn)	1 (1)
Number of days following injury when procedure was observed, mean±SD (range)	3.24±0.99 (1–6)
Procedure duration, mean±SD (range), min:sec	12:28±3:33 (5:57–23:25)
Number of pharmacological intervention, mean±SD (range)	1.98±0.63 (1–4)

SD=Standard Deviation; $AUD=Australian Dollars; %TBSA=Percentage of total body surface area burned.

3.5.2 Inter-coder reliability

The primary coder coded all 87 medical procedures, and the secondary rater coded 18 (20%) transcripts, and a further 15 (17%) nonverbal live observations. Table 3.4 reports the inter-coder reliabilities for parent and child behavior in the main sample. Inter-coder reliability was good to excellent. The average ICC for verbal child behavior was .90, and for nonverbal child behavior was .85. The average ICC for verbal parenting behavior was .87, and for nonverbal parenting behavior was .83. Although nonverbal behaviors aggression (child) and unengaged distress (parent) were not observed during the 15 selected live observations, it was observed by the primary coder during other observations and therefore retained in the final version of the B-CAMPIS.

Table 3.4 Inter-coder reliability of behavior

Behavior	ICC	Ratings of agreements*
Child behavior		
Verbal (N=18)		
Cry	.99	Excellent
Scream	.89	Excellent
Verbal Resistance	.92	Excellent
Emotional Support	.79	Good
Verbal Pain	.99	Excellent
Information Seeking	.90	Excellent
Non-procedural talk by child	.89	Excellent
Verbal Fear	.99	Excellent
Verbal Emotion	.80	Excellent
Making a coping statement	.80	Excellent
Breathing	.99	Excellent
Nonverbal (N=15)		
Play	.90	Excellent
Point	.60	Good
Requires restraint	.79	Good
Flail	.79	Good
Self soothe	.85	Excellent
Using the Ditto™ device	.93	Excellent
Watching television	.96	Excellent
Gaze to injury	.88	Excellent
Gaze to parent	.96	Excellent
Aggression	-	-
Parenting behavior		
Verbal (N=18)		
Criticism	.70	Good
Verbal reassurance	.97	Excellent
Giving control to the child	.93	Excellent
Apology	.62	Good
Empathy	.91	Excellent
Humor to child	.99	Excellent

Behavior	ICC	Ratings of agreements*
Nonprocedural talk to child	.86	Excellent
Command to engage in coping strategy	.93	Excellent
Prompting disclosure of pain	.79	Good
Threat to remove coping strategy	.99	Excellent
Negative evaluation	.88	Excellent
Nonverbal (N=15)		
Point to décor	.91	Excellent
Distract (play, action example, offer)	.78	Good
Reassuring Contact	.74	Good
Parent cry	.88	Excellent
Unengaged distress	-	-

*According to Cicchetti's (1994) interpretation.

3.5.3 Nature of additionally identified behavior

The tendency for additional behaviors to be grouped as *coping*, *distress*, *coping-promoting*, or *distress-promoting* was identified through examination of a Spearman's Rho correlation matrix consisting of all B-CAMPIS behaviors and the previously established CAMPIS-R coping, distress, coping-promoting, and distress-promoting behaviors.

Frequencies of using the Ditto™ device, gaze to injury, watching television, and aggressive behavior were associated with frequencies of previously validated child behaviors. Using the Ditto™ device was positively associated with coping behaviors (making a coping statement, r_s=.30, p=.005; non-procedural talk by the child, r_s=.37, p<.001), and negatively associated to distress behaviors (crying, r_s= -.26, p=.016; requiring restraint, r_s=-.24, p=.027). Gaze to injury was positively related to one coping behavior (making a coping statement, r_s=.21, p=.049), and negatively associated with distress behaviors (crying, r_s= -.37, p<.001; screaming, r_s=-.38, p<.001; flail, r_s=-.34, p=.001; requiring restraint, r_s=-.36, p=.001). Understandably, watching television was negatively associated with the coping behavior (playing, r_s=-.22, p=.040), however watching television was also negatively associated with the distress behaviors (screaming, r_s=-.23, p=.031; verbal resistance, r_s=-.23, p=.031). Aggressive behavior was only negatively associated with gaze to injury (r_s=-.28, p=.009). Therefore, the additional behaviors using the Ditto™ device, gaze to injury and watching television were added to the child coping category, and aggressive behavior was added to the child distress category.

Parenting behavior

Frequencies of negative evaluation of the wound, prompting disclosure of pain, threatening to remove coping strategy, crying, and unengaged distress were associated with frequencies of previously validated parenting behaviors. Negative evaluation of the wound was positively associated with distress-promoting behaviors (empathy, r_s=.26, p=.014; threat to remove coping strategy, r_s=.31, p=.003). Prompting disclosure of pain tended to be associated with distress-promoting behaviors (giving control to the child, r_s=.19, p=.085; empathy, r_s=.19, p=.077). Surprisingly, threat to remove coping strategy was positively associated with one coping-promoting behavior (command to engage in a coping strategy, r_s=.31, p=.004), but it was also associated with a distress-promoting behavior (verbal reassurance, r_s=.29, p=.007). Crying was negatively associated with one coping-promoting behavior (distract, r_s=-.23, p=.033). Unengaged distress was positively associated with a negative evaluation of the wound (r_s=.23, p=.031), and threat to remove coping strategy (r_s=.29, p=.007). Therefore, negative evaluation of the wound, prompting disclosure

of pain, threatening to remove coping strategy, crying, and unengaged distress were added to the parental distress-promoting category.

The nature of parental reassuring contact required additional analyses as previous measures code it differently. In the current study, reassuring contact was positively related to other distress-promoting behaviors verbal reassurance (r_s=.31, p=.004), and giving control to the child (r_s=.24, p=.023), however, it was not associated with any coping-promoting behaviors. Therefore, reassuring contact was added to the parental distress-promoting category in the B-CAMPIS.

3.5.4 Child development

The effect of child development on displayed behavior was assessed by categorizing children into age groups. Table 3.5 demonstrates the median rate of child behavioral frequency per minute by child age. Kruskal-Wallis tests demonstrated that child behavior (making a coping statement, non-procedural talk by child, crying, verbal resistance, seeking emotional support, verbal pain, verbal emotion, information seeking, self-soothing, requiring restraint, using the Ditto™ device, and gaze to injury) was significantly affected by child age ($Hs(2)\geq6.48$, $ps\leq.039$). Jonckheere's test revealed significant trends in the data: As the children increased in age, the rate of some child behaviors (making a coping statement, non-procedural talk by child, verbal resistance, verbal pain, verbal emotion, information seeking, using the Ditto™ device) increased ($Js\geq1414.5$, $zs\geq2.47$, $rs\geq.27$). In comparison, the rate of other child behaviors (crying, self-soothing, requiring restraint) decreased as the children increased in age ($Js\leq1025.5$, $zs\leq-2.03$, $rs\geq.22$). Significant trends were not found across child age for seeking emotional support or gaze to injury. One difference was found in the rate of parental behavioral frequency (empathy) between child age groups ($H(2)=6.52$, $p=.038$). Jonckheere's test revealed that as the children increased in age, parent verbal behavior empathy decreased ($J=1030.5$, $z=-1.86$, $r=-.20$).

Table 3.5 Median rate of behavior per minute and interquartile range by child's age

Behavior (*N*=87)	1-year-old (*n*=33)		2-years-old (*n*=23)		3–6-years-old (*n*=31)	
	Median	*IQR*	*Median*	*IQR*	*Median*	*IQR*
Child behavior						
Verbal						
Making a coping statement	0.00	0.00-0.00	0.00	0.00-0.12	0.00	0.00-0.18
Non-procedural talk by child	0.00	0.00-0.19	0.00	0.00-0.48	0.42	0.00-1.16
Breathing	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Cry	1.94	0.85-4.46	1.68	0.00-4.34	0.08	0.00-2.45
Scream	0.00	0.00-0.23	0.00	0.00-0.18	0.00	0.00-0.00
Verbal Resistance	0.00	0.00-0.00	0.00	0.00-0.14	0.00	0.00-0.21
Emotional Support	0.00	0.00-0.18	0.21	0.00-0.58	0.00	0.00-0.34
Verbal Fear	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Verbal Pain	0.00	0.00-0.17	0.17	0.00-0.31	0.41	0.00-1.41
Verbal Emotion	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Information Seeking	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Nonverbal						
Self soothe	0.00	0.00-0.33	0.13	0.00-0.68	0.00	0.00-0.00
Requires restraint	0.35	0.05-0.77	0.18	0.00-0.54	0.00	0.00-0.07
Flail	0.21	0.00-0.70	0.13	0.00-0.34	0.00	0.00-0.24
Play	0.09	0.00-0.38	0.00	0.00-0.18	0.00	0.00-0.00
Point	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00

Behavior (*N*=87)	1-year-old (*n*=33)		2-years-old (*n*=23)		3–6-years-old (*n*=31)	
	Median	*IQR*	*Median*	*IQR*	*Median*	*IQR*
Gaze to parent	0.00	0.00-0.21	0.00	0.00-0.18	0.15	0.00-0.38
Watch television	0.00	0.00-0.18	0.00	0.00-1.01	0.00	0.00-0.20
Using the Ditto™ device	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.79
Gaze to injury	0.71	0.15-1.10	1.25	0.79-1.90	0.85	0.30-1.37
Aggression	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Parenting behavior						
Verbal						
Criticism	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.16
Verbal reassurance	0.23	0.57-1.85	0.40	0.00-0.94	0.34	0.00-1.05
Giving control to the child	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Apology	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Empathy	0.00	0.17-0.46	0.00	0.00-0.17	0.00	0.00-0.26
Humor to child	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Nonprocedural talk to child	0.25	0.55-1.49	0.36	0.00-1.29	0.70	0.34-1.54
Command to engage in coping strategy	0.00	0.28-0.86	0.27	0.00-1.01	0.24	0.09-0.94
Prompting disclosure of pain	0.00	0.00-0.09	0.00	0.00-0.00	0.00	0.00-0.18
Threat to remove coping strategy	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Negative evaluation	0.00	0.00-0.20	0.00	0.00-0.23	0.00	0.00-0.14
Nonverbal						
Point to décor	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00

Behavior (*N*=87)	1-year-old (*n*=33)		2-years-old (*n*=23)		3–6-years-old (*n*=31)	
	Median	*IQR*	*Median*	*IQR*	*Median*	*IQR*
Distract (play, action example, offer)	0.00	0.30-0.68	0.12	0.00-0.38	0.15	0.00-0.29
Reassuring Contact	0.06	0.81-1.15	0.34	0.13-0.73	0.61	0.18-1.02
Parent cry	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00
Unengaged distress	0.00	0.00-0.00	0.00	0.00-0.00	0.00	0.00-0.00

IQR=interquartile range.

3.5.5 Convergent and discriminant validity

Descriptive statistics for each category of the B-CAMPIS (behavioral frequency per minute) are presented in Table 3.6. Spearman's Rho correlations were conducted to test the convergent and discriminant validity of the B-CAMPIS rate scores against the CAMPIS-SF scales and the CAMPIS-R rate scores. Specifically, 8 corresponding behavioral categories were tested for convergent validity (i.e., the B-CAMPIS child coping behavior to the CAMPIS-SF/CAMPIS-R child coping behavior) and 8 contradictory behavior categories were tested for discriminant validity (i.e., the B-CAMPIS child coping behavior to the CAMPIS-SF/CAMPIS-R child distress behavior). Out of 8 correlations examined for convergent validity, all 8 were positively significant at $p<.001$. Inspection of the confidence intervals revealed all of the B-CAMPIS behavior categories showed stronger associations to the CAMPIS-R behavior categories, compared to the CAMPIS-SF behavior categories. The greatest differences were seen on the parent categories: The B-CAMPIS parent behavior categories were strongly (>.70) associated to the CAMPIS-R parent behavior categories but only weakly to moderately (.30–.70) associated to the CAMPIS-SF parent behavior categories. Regarding discriminant validity, there was greater variation. Out of 8 correlations examined for discriminant validity, 6 were positively significant at $p<.05$. Inspection of the confidence intervals revealed the B-CAMPIS child coping category was weakly to moderately (.30–.70) negatively associated to CAMPIS-SF/CAMPIS-R child coping categories. The B-CAMPIS child distress category was moderately to strongly (-.64–-.83) negatively associated to the CAMPIS-SF child distress category but less so (-.51–-.13) to the CAMPIS-R child distress category. The B-CAMPIS parent behavior categories were less discriminant: There was no significant relationship to the contradictory CAMPIS-SF parent behavior categories. Although small relationships were seen between the B-CAMPIS and CAMPIS-SF/CAMPIS-R parent behavior categories, the confidence intervals suggest this relationship may not be legitimate.

Table 3.6 Spearman's Rho correlations between B-CAMPIS, CAMPIS-SF, and CAMPIS-R child categories (frequency of behavior per minute)

	B-CAMPIS categories			
	Child coping (95%CI)	Child distress (95%CI)	Parent coping-promoting (95%CI)	Parent distress-promoting (95%CI)
Median	2.10	2.34	1.39	1.69
Range	0-12	0-20	0-13	0-15
B-CAMPIS categories				
Child coping behavior	-	-.57*** (-.70–-.41)	.25* (.04–.44)	-.24* (-.43–-.03)
Child distress behavior		-	-.07 (-.28–.14)	.47*** (.29–.62)
Parent coping-promoting behavior			-	.28** (.07–.46)
Parent distress-promoting behavior				-
CAMPIS-SF categories				
Child coping behavior	**.63*** (.48–.74)**	-.75*** (-.83–-.64)	.18 (-.03–-.38)	-.43*** (-.59–-.24)
Child distress behavior	-.52*** (-.66–-.35)	**.78*** (.68–.85)**	-.06 (-.27–.15)	.50*** (.32–.64)
Parent coping-promoting behavior	.30** (.10–.48)	-.36** (-53–-.16)	**.55*** (.38–.68)**	.07 (-.14–.28)
Parent distress-promoting behavior	-.29** (-.47–-.09)	.45*** (.27–.60)	.03 (-.18–.24)	**.49*** (.31–.64)**
CAMPIS-R categories				
Child coping behavior	**.67*** (.54–.77)**	-.33** (-.51–-.13)	.12 (-.09–.32)	-.24* (-.43–-.03)
Child distress behavior	-.50*** (-.64–-.32)	**.98*** (.97–.99)**	-.09 (-.30–.12)	.47*** (.29–.62)
Parent coping-promoting behavior	.25* (.04–.44)	-.07 (-.28–.14)	**.97*** (.96–.98)**	.32** (.12–.50)
Parent distress-promoting behavior	-.22* (-.41–-.01)	.59*** (.43–.71)	.26* (.05–.45)	**.86*** (.79–.91)**

B-CAMPIS=Burns-Child-Adult-Medical Procedure Interaction Scale; CAMPIS-SF=Child-Adult-Medical Procedure Interaction Scale; CAMPIS-R=Child-Adult-Medical Procedure Interaction Scale-Revised; CI=Confidence Interval. Bolding indicates the convergent validity analyses and underlining indicates that discriminant validity analyses. $^{***}p<.001$, $^{**}p<.01$, $^{*}p<.05$.

3.5.6 Incremental validity

Linear regressions were conducted to variance accounted for by the B-CAMPIS child categories compared to the existing CAMPIS-R child categories on nurse-report pain-related behavioral distress score (FLACC), parent-report child procedural pain score, and parent-report child procedural fear score. See Table 3.7 for results. The B-CAMPIS child distress category accounted for slightly more variance in the variability of nurse-reported child behavioral distress (B-CAMPIS=46%, CAMPIS-R=44%), and equivalent variability in parent-reported child procedural pain (B-CAMPIS=26%, CAMPIS-R=26%) and parent-reported child procedural fear (B-CAMPIS=26%, CAMPIS-R=26%). The B-CAMPIS child coping category accounted for more variability in nurse-reported child behavioral distress (B-CAMPIS=16%, CAMPIS-R=0%), parent-reported child procedural pain (B-CAMPIS=5%, CAMPIS-R=0%) and parent-reported child procedural fear (B-CAMPIS=17%, CAMPIS-R=4%) scores.

Table 3.7 Twelve univariate linear regression analyses demonstrating the predictive natures of the B-CAMPIS and CAMPIS-R child categories on parent- and nurse-reported measures of child distress

Predictor	Nurse-reported pain-related distress behavior (*N*=87)				Parent-reported procedural pain (*N*=85)				Parent-reported procedural fear (*N*=85)			
	F	*β*	*p*	R^2	*F*	*β*	*p*	R^2	*F*	*β*	*p*	R^2
Child coping behavior												
CAMPIS-R	0.06	-.03	.812	.00	0.00	.00	.996	.00	3.04	-.20	.085	.04
B-CAMPIS	16.61	-.40	<.001	.16	5.10	-.24	.027	.05	15.92	-.41	<.001	.17
Child distress behavior												
CAMPIS-R	59.95	.66	<.001	.44	27.40	.51	<.001	.26	27.18	.51	<.001	.26
B-CAMPIS	65.81	.68	<.001	.46	27.57	.51	<.001	.26	26.90	.51	<.001	.26

B-CAMPIS=Burns-Child-Adult-Medical Procedure Interaction Scale; CAMPIS-R=Child-Adult-Medical Procedure Interaction Scale-Revised.

3.6 Discussion

The aims of this chapter were to develop and test the reliability and validity of the B-CAMPIS, an extension of the CAMPIS-R observational measure. There was a gap in the field for an observational measure to assess parent-child interactions during burn wound care, and particularly for young children who are commonly at greater risk of procedural distress, as well as sustaining a burn injury. Several additional child and parent behaviors were identified and added to the B-CAMPIS. As the Ditto™ device (currently used in pediatric burn centers across the UK, USA, and Australia) and television watching are common methods of distraction for coping (Koller & Goldman, 2012), it was important to include these behaviors. In comparison, increased gaze to injury was an unexpected child coping behavior, despite a minority of children who displayed increased distress at the sight of the wound. The literature regarding watching painful procedures is mixed: An observational study of adults found those who spontaneously looked away reported higher pain intensity and suggested that observation can have an analgesic effect (Vijayan, Scott, & Brownlie, 2015). However, a randomized controlled trial of adults found watching *and* preferring to look away individually increased fear but not pain (Mithal et al., 2018). A key driver of pain intensity appears to be pain expectation (Höfle, Hauck, Engel, & Senkowski, 2012), and preferred coping style of the child (i.e., approach vs. avoidant coping style) should be considered before encouraging this specific coping strategy (Blount, Davis, Powers, & Roberts, 1991). Parental reassuring contact was uniquely associated with distress-promoting behaviors in this sample. Research on infants demonstrate the analgesic benefits of contact (Johnston et al., 2014). However, for young children it appears that reassuring contact is more likely to be present with other distress-promoting behaviors, than coping-promoting behaviors.

Inclusion of the additional child behaviors allowed the B-CAMPIS to reflect child coping and child distress across the developmental stages of children 1–6-years-old. Previous measures have not reported differences across age groups (Caldwell-Andrews et al., 2005). Older children displayed higher frequencies of verbal behaviors and using the Ditto™ device, and this was expected because young children do not have the vocabulary and metacognitive skills for these behaviors (N. J. Brown, Kimble, Rodger, Ware, & Cuttle, 2014; McGrath & Frager, 1996). Younger children showed higher frequencies of crying and required more physical restraint, which also aligns with the literature (Young, 2005).

The B-CAMPIS showed convergent and incremental validity compared CAMPIS-SF and CAMPIS-R behavior categories for parent and child. Less associations were noted for the discriminatory analyses. While child coping behavior was negatively correlating to child distress behavior, parent

coping-promoting behavior was unlikely to be related to parent distress-promoting behavior. Rather than suggesting evidence of non-validity, we propose that this indicates that coping-promoting behavior and distress-promoting behavior is not on a continuum. Parents can engage in both behaviors concurrently, likely in an effort to "try anything" to regulate their child's behavior in the absence of a recommended approach. Therefore, the B-CAMPIS was overall found to be a valid measure of parent and child behavior during burn wound care. Future research should continue to disentangle the relationship between parenting behavior and child coping outcomes. The B-CAMPIS also appeared to account for more variability in parent- and nurse-reported child distress scores, particularly through identifying young child coping behavior and is a strength of the measure.

3.6.1 Clinical and research applications

The B-CAMPIS can be used in a variety of research and clinical contexts. Further validation is required to ensure the B-CAMPIS is acceptable in different centers. The field of pediatric burns has limited evidence-based resources for intervening to reduce procedural distress. The addition of the B-CAMPIS will assist researchers to design studies to better understand and support the important role parents play in influencing child distress during pediatric burn wound care. Understanding the parent's role can lead to the development of parent-level interventions, for example, training and reinforcing beneficial behaviors during pediatric burn wound care. Interventions may also consider adequate information provision and instructing parents to avoid communicating fear to their child by not reacting to the sight of the injury. With regards to clinical application, it may not be feasible for healthcare professionals to code frequency of behaviors. However, healthcare professionals can still be aware of the range of evidence-based influential behaviors, in terms of their own interactions with the child, as well as the behaviors they encourage parents to use. Concerns have been raised previously regarding the potential for parental distress during pediatric burn wound care (Stoddard et al., 2002), however, recent research has highlighted that parents generally prefer to be present (Egberts, de Jong, et al., 2018). With an increasing focus towards family-centered care, it is important for parents to feel empowered to assist their child during wound care, and providing the parents with an explicit role such as distraction may be extremely helpful for the child as well as the parent.

3.6.2 Limitations and future directions

While it was a strength of the current study to test multiple types of validity, and validate child and parent behaviors, there were also some limitations to report. It is a limitation that the B-CAMPIS was not compared against observational procedural distress measures separate from the CAMPIS

coding scheme (i.e., OSBD, CHEOPS), because repeated items inflated validity scores. However, with live coding nonverbal behavior, it was not feasible for multiple observational measures to be used. Another weakness was to exclude analyzing healthcare professional behavior. It is possible that parenting behaviors in the B-CAMPIS can be applied for assessing healthcare professional interactions during burn wound care. Further work could validate healthcare professional behavior within a burn wound care context.

The current research has built on the existing framework of the CAMPIS-R, which was designed with six categories. The B-CAMPIS was designed to emulate the CAMPIS-R constructs, however, neutral categories were omitted. The field often omits neutral categories likely due to the assumption that they are not influential, however, further research should be conducted to support or discredit this assumption. While a factor analysis would be beneficial in theory, the B-CAMPIS scores behaviors that have a broad range of frequency of occurrence and also the frequency of behaviors can differ significantly across the age groups assessed in this study. As such, a factor analysis would not be helpful in this case.

3.6.3 Conclusions

Creating the B-CAMPIS is important for future research to be able to quantify parent and child interactions during pediatric burn wound care. Young children are an important yet under studied population regarding interventions for improving coping during burn wound care. Understanding the parents' and child's experiences during wound care can inform the development of targeted behavioral interventions, with the aim of reducing distress experienced by the child and their parents.

Chapter 4. Impact of parental acute psychological distress on young child pain-related behavior during pediatric burn wound care

Brown, E. A., De Young, A. C., Kimble, R., & Kenardy, J. (2019). Impact of parental acute psychological distress on young child behavior through changes in parenting behavior during burn wound care. *Journal of Clinical Psychology in Medical Settings*. doi: 10.1007/s10880-018-9596-1

4.1 Contribution to authorship

The design of this study was shared between myself (80%) and my supervisors. I collected the data (100%). I am responsible for the statistical analyses (100%) and interpretation of the results (100%). I am responsible for writing the paper (100%), which my supervisors provided detailed feedback.

4.2 Preamble

As identified in Chapter 1, the influence of parental psychological distress has been alluded to but not previously reported in the context of pediatric burn wound care. This chapter tested the model of the relationship between parental psychological distress and child procedural distress presented in Chapter 1, utilizing the measure developed and validated in Chapter 2. This chapter investigated a range of parental acute psychological distress symptoms and found differences, which prompted modifications to the proposed theoretical model. This chapter comprises of a paper that has been published in *Journal of Clinical Psychology in Medical Settings*, with minor modifications.

4.3 Introduction

Parents have been identified as one of the single most important predictors of young child procedural distress (Pillai Riddell, Gennis, Taddio, & Racine, 2016; Pillai Riddell & Racine, 2009; Racine, Pillai Riddell, Flora, et al., 2016). As young children are reliant on their parents for emotion co-regulation (Ainsworth et al., 1978), it is likely that young children are particularly attentive to their parents' reactions during stressful events such as medical procedures (Hornik & Gunnar, 1988; van der Kolk, 1987). During pediatric medical procedures, parenting behavior has been found to influence child behavior and pain intensity (Blount et al., 1989; Chambers et al., 2002; Cohen, Manimala, & Blount, 2000; MacLaren Chorney et al., 2009; Manimala et al., 2000; Sweet & McGrath, 1998). Specifically, parenting behavior that encourages child coping includes engaging the child in distracting tasks or deep breathing exercises, while parenting behavior that increases child procedural distress includes excessive reassurance, empathy, and giving control to the child (Blount et al., 1997). Procedural distress is generally linked to pain (see von Baeyer & Spagrud, 2007, for a review), and is thought to contribute to long-term consequences such as chronic pain (Kehlet, Jensen, & Woolf, 2006; Perkins & Kehlet, 2000), increased pain sensitivity (Buskila et al., 2003; Taddio et al., 1997; Weisman, Bernstein, & Schechter, 1998), and anticipatory fear (Pate, Blount, Cohen, & Smith, 1996; Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002). Therefore minimizing pediatric procedural distress is of benefit, and understanding the role parents play in their child's distress during procedures has significant value.

While much of the research has been conducted in immunization cohorts (i.e., Cohen et al., 2005), further consideration of the hospitalized medical procedures that children undergo following an injury or illness diagnosis is needed. The onset of a pediatric injury or illness can be highly distressing for the child and the parents. A recent review of the literature identified that in the wake of a child's injury/illness diagnosis, a proportion of parents report psychological distress, which may affect how they interact with their child during subsequent medical procedures (Chapter 1, published as E. A. Brown et al., 2018b). The proposed mechanism is that parents with psychological distress are thought to be less able to respond to their child's needs (Slade, 2007). Specifically, Brown et al. proposed a conceptual model, suggesting differences in parental procedural behavior mediated a relationship between parental psychological distress (general anxiety, posttraumatic stress) and child procedural distress. The model is presented in Figure 1.1 (Chapter 1, page 21).

Research testing the mechanism between parent distress and child distress during medical procedures is limited. One study has investigated the role of parental distress on child behavior

during immunizations, mediated through parenting behavior (Bernard, 2001). The authors did not find an effect, although methodological differences compared to the current investigation may have contributed. Firstly, routine immunization is not usually associated with the same level of psychological distress as procedures relating to a child's hospitalized injury or illness. Therefore, the measure of parental distress ("How distressed were you (during the procedure)?") is a state measure rather than attempting to identify psychological distress (i.e., excessive worrying, avoidance, intrusive thoughts, depressed affect etc.) stemming from the injury or diagnosis. Secondly, evidence suggests that the impact of parenting behavior on procedural distress does not develop until the child is approximately 1-year-old (Pillai Riddell et al., 2011). Children in the study by Bernard and colleagues were 0–2-years-old. Therefore, we would not expect the effect to be present for approximately half of the cohort. Finally, a newer method for mediation has been developed to test indirect effects (Hayes, 2013). This paper aims to address these limitations and to test Brown's model.

Burn wound care is an under-researched area with a high prevalence of procedural pain and psychological distress (Stoddard et al., 2002). Children under 6-years-old are at high risk of sustaining a burn injury (Duke et al., 2011) and subsequently make up the majority (62%) of pediatric burn injury admissions (Stockton et al., 2015). The burn injury and required wound care (debriding and cleaning before redressing the wound) cumulatively contribute to the pain experience (Connor-Ballard, 2009; Weinberg et al., 2000). Providing adequate burn wound care analgesia is difficult due to changes in physiology that increase pain sensitivity (Connor-Ballard, 2009; Sharar et al., 2008), and reduce the effectiveness of pharmacologic intervention (because it is processed more quickly by the metabolism) (Cooper & Pavlin, 1990). Additionally, clinicians are at risk of under-treating child pain during burn wound care because of wariness of medication side-effects (i.e., nausea, respiratory failure, etc.) and potential opioid addiction (Connor-Ballard, 2009; Melzack, 1990). Of further concern, children under 5-years-old have more trouble accurately self-reporting pain intensity (von Baeyer et al., 2017) and clinicians can interpret distress behavior as fear rather than pain (McGrath & Frager, 1996).

To date, no known study has investigated parenting behavior during pediatric burn wound care. Parents prefer to be present during pediatric burn wound care (Egberts, de Jong, et al., 2018; Morley et al., 2017), but concerns have been raised previously regarding the parent's own acute psychological distress inhibiting providing effective support (Stoddard et al., 2002). Following a pediatric burn injury, children and their parents can each have acute psychological distress reactions (Bakker et al., 2013; De Young et al., 2014; McGarry et al., 2014; McGarry et al., 2013). Up to 50% of parents report clinically significant acute traumatic stress (Bakker et al., 2012), and 6%

experience chronic PTSS (De Young et al., 2014). Parents commonly report strong guilt (Bakker et al., 2010), which is likely related to perceived failure to protect their child (during the unintentional injury and subsequent treatment), and the constant visual reminder of the wound/scar (Mason, 1993). Up to 23% of parents also report acute general anxiety/depression symptoms (De Young et al., 2014). Parental fear has only been qualitatively assessed in pediatric burn populations (McGarry et al., 2015), but has been found to influence child pain/fear in other procedures (Bearden et al., 2012). When encouraging parents to be present throughout burn wound care, it is important to understand how parental acute psychological distress might influence their child's procedural behavior.

The aim of this study is to test Brown's conceptual model by observing the first burn dressing change for young children (1–6-years-old). Focusing on the first dressing change will isolate the impact of the parent's acute psychological distress relating to the injury itself (rather than the cumulative distress of witnessing the child's dressing change/s). As discussed in Chapter 1, the psychological distress variables described above have a combination of unique and overlapping symptomologies which may influence parenting behavior differently, despite current theoretical models indicating a uniform influence. Therefore, it is pertinent to test each parental distress variable individually to confirm or challenge current theoretical thought. A series of 8 mediational analyses will be conducted to establish the effect of parental acute psychological distress (that is, the four measures of PTSS, pre-procedural fear, general anxiety/depression symptoms, and guilt) on child procedural behavior through differences in parenting behavior. Specifically, it is hypothesized that the parental acute psychological distress variables will indirectly reduce child coping through less parental coping-promoting behavior (4 mediations); and increase child distress through more parental distress-promoting behavior (4 mediations).

4.4 Method

4.4.1 Setting

The PLCBC at the Queensland Children's Hospital, Brisbane, Australia, is a tertiary-level pediatric burns center. The PLCBC receives approximately 1,000 new burn referrals per year. When a child presents to a general practitioner, a different hospital's emergency department, or this hospital's emergency department, the referral center will be contacted prior to application of the initial dressing. The center uses and recommends silver-impregnated dressings that remain in place for approximately 3 days, as supported by the literature (that is, more cost-effective, quickens healing, and reduces pain during dressing changes compared to using daily silver-based ointment dressings)

(Gee Kee, 2016). The center requests most children to present at the outpatients clinic for the first dressing change.

The center does not employ child life therapists or psychologists; therefore, there is no professional support role for minimizing procedural distress. Occupational therapists can step in to provide procedural support for extreme cases. In two cases, volunteer clown doctors were present for part of the dressing change. There are a small number of toys in each treatment room, although these are not used during the procedure. The center does use the Ditto™ electronic distraction device (Diversionary Therapy Technologies, Queensland, Australia), which a multi-modal preparation and distraction device validated use with children 4–12-years-old undergoing burn wound care. Pediatric burn centers across the UK, USA, and Australia currently use the Ditto™ device. Additionally, televisions are in each treatment room. The Ditto™ device and television is used at the discretion of the treating nurse (and the Ditto™ was only developmentally appropriate for the older children in the current study). Therefore, as an observational study, a proportion of children were exposed to some coping strategies throughout their treatment. Parents are not given any information regarding what to expect (such as procedural information, expectations, likelihood of immediate surgery, or approximate appointment time) prior to the dressing change.

4.4.2 Participants and design

Parents of children aged 1–6-years-old who presented to the center following an unintentional burn injury were recruited at the first dressing change. In this sample, the first dressing change consisted of the removal of the first dressing (applied on day of injury), debridement and washing of the wound, and the application of a second dressing. Clinically, the first dressing change is considered the most painful burn wound care appointment. It was important to recruit only families about to undergo the first dressing change because they will not have pre-existing negative expectations that exacerbate procedural distress or a previously developed pattern of behavior during the procedure.

Per standard procedure, all children were given a combination of oral and/or nasal premedication (oxycodone, paracetamol, ibuprofen, midazolam, and/or fentanyl) prior to first dressing change and debridement. The range of premedication was based on the treating nurse's clinical judgment of anticipated pain based on previous photos and descriptions of the wound. Weight-appropriate quantities of the premedication were approved by a doctor. Participants were excluded if 1) the child had a developmental disorder (e.g., autistic spectrum disorder), or; 2) comorbid head injury (Glasgow Coma Scale < 12); 3) the child's injury was suspected to be due to abuse or neglect; 4) the primary caregiver was not present for the child's dressing change; 5) the parent spoke insufficient English for completing questionnaires and verbal coding, or; 6) the child was taken to

the operating theatre and therefore the dressing was changed under general anesthetic. In cases where both parents were present for the dressing change, one parent self-nominated to take part in the study. All participating parents provided written informed consent. All children were under the age of 7-years-old and therefore not required to give assent. The University of Queensland Human Research Ethics (2015000623) and the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC/15/QRCH/27) approved this study.

4.4.3 Measures

Parents reported sample characteristics and their psychological distress symptoms. The researcher coded parent and child behavior during the dressing change.

Sample characteristics

Parents completed a questionnaire regarding family demographic information and the child's medical background. Family sample characteristic information included parent and child genders, ages, ethnic backgrounds, and annual household income. Information regarding the injury and the first dressing change was collected through medical records. This data included injury mechanism, wound depth, percentage of total body surface area burned (%TBSA), number of pharmacological interventions utilized at the first dressing change, and number of days following the injury when the dressing change occurred. The sample characteristics have been previously reported in Chapter 3.

Parental psychological distress

Posttraumatic stress symptoms. The Primary Care-Post-Traumatic Stress Disorder screen (PC-PTSD; Prins et al., 2003) consists of four items that correspond with the four symptom factors that underlie the Diagnostic and Statistical Manual for Mental Disorders, 4th Edition (DSM-IV) criteria for PTSD (American Psychiatric Association, 1994). Respondents indicated yes or no about symptoms experienced "since your child's accident". The PC-PTSD has a high test-retest reliability, and good sensitivity and specificity rates with a cut-off score of 3 (Spoont et al., 2013). The PC-PTSD screen has also been analyzed as a symptom count (Jaycox et al., 2009), which the current study used.

General anxiety/depression symptoms. The Patient Health Questionnaire for Depression and Anxiety-4 (PHQ-4) is a 4-item screen for general anxiety/depression symptoms (Kroenke, Spitzer, Williams, & Lowe, 2009). Participants are asked to report the frequency of symptoms during the past 2 weeks, on a 4-point scale from 0 (*not at all*) to 3 (*nearly every day*). Scores can be summed to indicate none (0–2) mild (3–5), moderate (6–8) or severe (9–12) levels of general anxiety/depression symptoms. The PHQ-4 has been tested for reliability (αs>.80), construct validity

(α=.85), and factorial validity (factor loadings >.82) (Kroenke et al., 2009). In the current study, this measure was used as a symptom count. Cronbach's α was .86 in the present study.

Pre-procedural Fear. The Visual Analogue Scale for Anxiety (VAS-A; Choiniere et al., 1989) is a single item measure of pre-procedural fear. A continuous line of 10cm in length is anchored by *no anxiety or fear* on the left and *worst possible anxiety or fear* on the right, and participants are asked to mark where on the line reflects their current level of fear. The VAS-A has been validated as an accurate self-report of anxiety in adult populations (Choiniere et al., 1989).

Guilt. The Global Guilt Scale (GGS; Kubany et al., 1996) is a 4-item subscale of the Trauma-Related Guilt Inventory that assesses intensity of guilt feelings. The Trauma-Related Guilt Inventory has high internal consistency, and the subscales have been validated in other traumatized populations through correlations to other guilt, PTSD, and depression measures (Kubany et al., 1996). Participants were asked to respond to the GGS in relation to their child's unintentional injury. In this study, Cronbach's α was excellent: .94.

Behavioral coding

The B-CAMPIS was specifically developed to assess parent-young child interactions during pediatric burn wound care (see Chapter 3 for further description). The B-CAMPIS is a reliable measure, and convergent and incremental validity have been established (see Chapter 3).

4.4.4 Procedure

A researcher screened potential participants for eligibility and approached them on arrival to the outpatient's clinic to obtain informed consent. Recruitment occurred from September 2015 to June 2016. Of 1,864 presentations, 152 families were eligible for recruitment. Fifty families were not approached because the procedure began prior to recruitment, seven families were missed because they were enrolled in a conflicting research project, and one family was considered too distressed to approach. Therefore, 94 families were approached, and 92 families (98%) agreed to participate. Written consent was obtained, and the parent completed the demographic and mental health questionnaires in the waiting room. A researcher observed the dressing change for verbal (audio recorded) and nonverbal behavior (coded live), from the commencement of the dressing removal, to approximately 2 minutes after the wound was debrided and washed (unless the child left the room earlier). This part of a dressing change is clinically considered to have the greatest potential for distress and/or pain. Depending on the location of the wound, the child was positioned either on a hospital bed or on the parent's lap. Following washing, it is typical procedure to place plastic wrap over the wound for the consultant to assess the wound. After the consultant's assessment, nursing staff will most likely re-dress the wound. Dressing reapplication was not coded because the time

between debridement and reapplication can vary greatly due to the nature of a busy multidisciplinary clinic. For example, other specialists (occupational therapists, physiotherapists, social workers, researchers, etc.) may also visit the family during the appointment.

4.4.5 Statistical analyses

Descriptive statistics were presented using medians and inter-quartile ranges (*IQR*) for non-normally distributed behavioral data. Analyses were restricted to parents who completed the questionnaires. The current study limited analyses to models of a) parental coping-promoting behavior related to child coping behavior, and b) parental distress-promoting behavior related to child distress behavior. Because these groupings have the strongest associations, using this parameter assists to limit Type 1 error. Therefore, eight mediation analyses were conducted, to individually compare the effects of each predictor (parental PTSS, guilt, general anxiety/depression symptoms, and pre-procedural fear), on each mediator (parental coping-promoting/distress-promoting behavior), and corresponding outcome (child coping/distress behavior) Analyses were conducted using Model 4 in the PROCESS SPSS macro developed by Hayes (2013). Bias-corrected bootstrapping of 10,000 samples were utilized to estimate the indirect effects. Correlational analyses were undertaken with SPSS 24 for Windows to identify possible sample characteristic covariates to significant mediation models. Potential covariates were individually tested for significant relationships with outcomes at $p<.05$. All covariates with significance at below $p=.05$ were included to evaluate for a broad range of potential covariates, and best fit was tested using backwards elimination (Tabachnick, Fidell, & Osterlind, 2001). Power for the mediational analyses were computed using Webpower (Schoemann, Boulton, & Short, 2017; Zhang & Yuan, 2018). For power of .08, a sample size of 66 families was estimated, based on path *a* and path *b* at .5, and an α of .05. These parameters were chosen because a moderate effect size was expected based on previous research (National Research Council and Institute of Medicine Committee on Depression, 2009).

4.5 Results

4.5.1 Sample characteristics

The final sample consisted of 87 parent-child dyads. Five families were retrospectively excluded according to exclusion criteria (speaking a language other than English during the procedure, burn injury was superficial in depth, and wound mechanism was retrospectively attributed to an infection rather than burn). Children were predominantly male (*n*=50, 57%), Anglo/European (*n*=60, 69%), and had a mean age of 2.95 years (*SD*=1.72, range 1.00-6.90). Participating parents were predominantly mothers (*n*=73, 84%), Anglo/European (*n*=60, 79%) and had a mean age of 32.37

years (*SD*=5.31, range 22.00-43.00). The depth of burn injuries were classified as superficial-partial thickness (*n*=63, 72%), deep-partial thickness (*n*=21, 24%) or full thickness (*n*=3, 4%). The %TBSA ranged from 0.5% to 12% (*M*=1.87%, *SD*=2.14%). Four children (5%) subsequently required grafting and another 10 children (11%) subsequently required scar management. Therefore, the sample represents an injury group with relatively minor burn injuries, compared to previous research studies (De Young et al., 2014). Burn mechanism was most commonly scald (*n*=42, 48%) or contact (*n*=42, 48%), then friction (*n*=2, 3%), and sunburn (*n*=1, 1%). All participants were outpatients. The first dressing change occurred an average of 3.24 days following the injury (*SD*=0.99, range 1–6). The observed procedures were an average of 12:28 min:sec (*SD*=3:33, range 5:57–23:25) in duration, and conducted by 1–2 of 9 specialist wound care nurses.

4.5.2 Preliminary analyses

Pearson's and Spearman's correlation matrices were generated to identify relationships between parent and child behaviors, and sample characteristic (demographic and injury-related) variables. Child coping behavior was correlated to child age (r=.43, p<.001), and parent gender (mothers, r_s=-.40, p<.001). Child distress behavior was correlated to parent gender (mothers, r_s=.29, p=.006). Parental coping-promoting behavior was correlated to parent ethnicity (Anglo/European, r_s=-.31, p=.006), and child ethnicity (Anglo/European, r_s=-.37, p=.001). Parental distress-promoting behavior was not correlated to any sample characteristic variables. There was no difference between nurses and parent or child behavior and therefore was not controlled for in the subsequent analyses.

Descriptive information and the correlation matrix for the variables of interest are presented in Table 4.1 and Table 4.2, respectively. A minority of missing data was observed in the parental self-reported psychological distress measures. Two participants (2%) had responded to three of the four items on the PC-PTSD. In these cases, the participant mean was substituted for the fourth item. In addition, a minority of participants did not respond on any of the psychological distress measures: Nine (10%) parents did not respond on the PHQ-4, 6 (7%) parents did not respond on the VAS-A, 6 (7%) parents did not respond on the GGS, and 4 (5%) parents did not respond on the PC-PTSD screen. Missing values analysis revealed no significant differences between rates of parental coping-promoting or distress-promoting behavior and missingness on psychological distress measures. Therefore, the data was likely missing at random, and listwise deletion was employed if more than one item on each measure was missing. The final sample sizes for each associated mediation analysis is reported in Table 4.1. Specific behavioral frequencies within the B-CAMPIS categories are reported in Table 4.3. Frequencies by age group can be found in Chapter 3.

Table 4.1 Means and standard deviations of variables of interest

	N	*M (SD)*	Potential range	Sample range	Above clinical cut-off, *n* (%)
Parent					
PTSS	83	0.94 (1.14)	0–4	0–4	
No symptoms					41 (49)
1 symptom					19 (23)
2 symptoms					12 (14)
3 symptoms (clinical cut-off)					9 (11)
4 symptoms					2 (2)
General anxiety/depression symptoms	78	1.44 (2.30)	0–12	0–11	
Mild					9 (12)
Moderate					5 (6)
Severe					1 (1)
Pre-procedural fear	81	2.58 (2.52)	0–10	0–9	
Guilt	81	6.54 (4.24)	0–16	0–16	
Coping-promoting behavior†	87	1.72 (1.49)		0–7	
Distress-promoting behavior†	87	2.32 (2.58)		0–15	
Child					
Coping behavior†	87	2.53 (1.87)		0–9	
Distress behavior†	87	4.02 (3.98)		0–20	

†Rate of behavior per minute during wound care.

Table 4.2 Inter-correlations for variables of interest for mediational analyses

	1.	2.	3.	4.	5.	6.	7.	8.
Parent								
1. PTSS	-	.57***	.40***	.44***	.24^	-.14	.10	-.25*
2. Guilt		-	.31**	.30**	.22*	-.05	.20^	-.35**
3. General anxiety/depression symptoms			-	.45***	-.05	-.31**	.02	-.14
4. Pre-procedural fear				-	-.03	-.20^	.16	-.26*
5. Distress-promoting behavior					-	.15	.46***	-.25*
6. Coping-promoting behavior						-	-.08	.33**
Child								
7. Distress behavior							-	-.50***
8. Coping behavior								-

***p<.001, **p<.01, *p<.05, ^p<.1

Table 4.3 Behavioral frequencies and interquartile range

Behavior (*N*=87)	*Median*	*IQR*
Child coping behavior		
Making a coping statement	0	0–0
Non-procedural talk by child	0	0–3
Breathing	0	0–0
Self soothe	0	0–2
Watch television	0	0–1
Gaze to injury	6	1–9
Play	0	0–2
Point	0	0–0
Gaze to parent	1	0–2
Using the Ditto™ device	0	0–0
Child distress behavior		
Cry	10	1–23
Scream	0	0–1
Verbal Resistance	0	0–0
Emotional Support	0	0–2
Verbal Fear	0	0–0
Verbal Pain	1	0–4
Verbal Emotion	0	0–0
Information Seeking	0	0–0
Requires restraint	1	0–3
Flail	1	0–3
Aggression	0	0–0
Parental coping-promoting behavior		
Point to décor	0	0–0
Humor to child	0	0–0
Nonprocedural talk to child	4	1–9
Command to engage in coping strategy	2	0–6
Distract (play, action example, offer)	1	1–3
Parental distress-promoting behavior		
Criticism	0	0–0
Verbal reassurance	3	0–8

Behavior (*N*=87)	*Median*	*IQR*
Giving control to the child	0	0–0
Apology	0	0–0
Empathy	0	0–1
Reassuring Contact	4	1–6
Prompting disclosure of pain	0	0–1
Threat to remove coping strategy	0	0–0
Negative evaluation	0	0–1
Parent cry	0	0–0
Unengaged distress	0	0–0

IQR=Interquartile range.

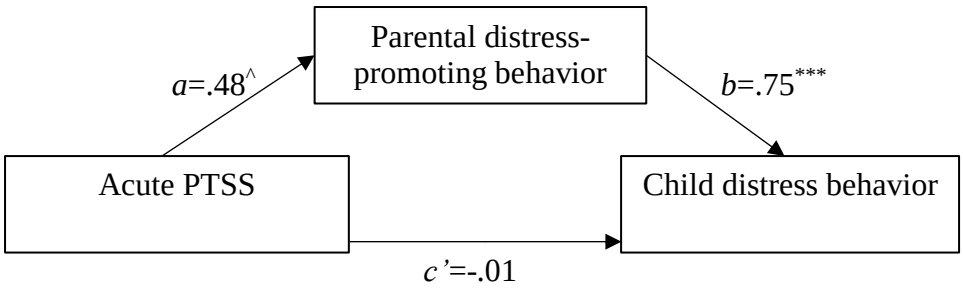
4.5.3 Mediation analyses

Analyses confirmed three significant mediations. Figure 4.1 presents the significant models, with covariates. In Model 1, child distress behavior was found to be predicted by parental acute PTSS and was mediated via parental distress-promoting behavior. In Model 2, child distress behavior was predicted by parental acute guilt, which was mediated via parental distress-promoting behavior. In Model 3, child coping behavior was predicted by parental acute general anxiety/depression symptoms and was mediated via parental coping-promoting behavior. Sample characteristic variables identified in the preliminary analyses were tested as covariates in the significant mediation models. Model fit for Models 1 and 2 were not significantly improved by the inclusion of covariates and therefore not retained in the final models. Model fit for Model 3 significantly improved with the inclusion of two covariates (child age, parent gender) and was therefore retained in the analyses. Table 4.4 presents the standardized indirect estimates for all analyses.

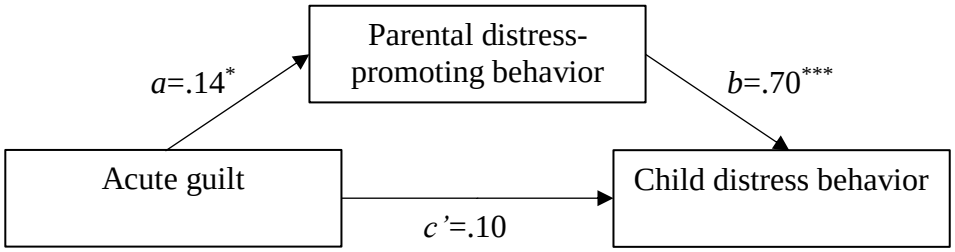
Table 4.4 Indirect effect of parental acute psychological distress on child behavior as mediated by parent behavior

Parental acute psychological distress (Predictor)	Parenting behavior (Mediator)	Child behavior (Outcome)	Indirect effect *ab* (*SE*)	Bootstrap 95% CIs Lower, Upper	Model
PTSS	Distress-promoting	Distress	.36 (.23)	0.01, 0.95*	1
Guilt	Distress-promoting	Distress	.09 (.06)	0.01, 0.26*	2
General anxiety/depression symptoms	Distress-promoting	Distress	-.03 (.08)	-0.17, 0.15	
Pre-procedural fear	Distress-promoting	Distress	-.02 (.06)	-0.13, 0.12	
PTSS	Coping-promoting	Coping	-.07 (.07)	-0.26. 0.01	
Guilt	Coping-promoting	Coping	-.01 (.02)	-0.06, 0.02	
General anxiety/depression symptoms	Coping-promoting	Coping†‡	-.06 (.03)	-0.14, -0.02*	3
Pre-procedural fear	Coping-promoting	Coping	-.04 (.03)	-0.13, 0.001	

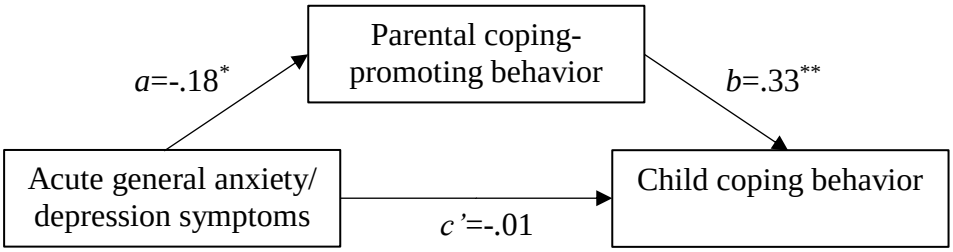
Notes. Confidence intervals have been corrected for bias. Bootstrapping of 10,000 samples has been conducted. Covariates added to models: †child age, ‡parent gender. *SE*=Standard Estimate, CI=Confidence Interval. *Significant mediation.



A. Model 1



B. Model 2



C. Model 3†‡

Figure 4.1 Significant Mediation models with direct effects

Note. Covariates added to models: †child age, ‡parent gender.

***p<.001, **p<.01, *p<.05, ^p<.1

4.6 Discussion

As hypothesized, the relationship between parent and child distress was mediated through parenting behavior. While the literature supports that parents experiencing PTSS/general anxiety to respond in a similar fashion, differences emerged. Parental PTSS/guilt was related to more frequent child distress behavior (i.e., crying, flailing) through more frequent distress-promoting behavior (i.e., excessive reassurance, empathy). The effect of PTSS/guilt on parenting behavior has not been researched previously. It is possible the injury-related guilt, hyper-arousal, and re-experiencing symptoms are activated through re-exposure to their child's distress during the related wound care procedures and trigger the parent to be provide more comfort (excessive reassurance, empathy) as a way to amend for failing to protect their child from the injury. However, their own emotional distress may be implicitly communicated to the child at the same time (crying, negative evaluation of the wound). As Slade (2007) theorized, it may be that that parental psychiatric symptoms impair the parent's ability perceive and accurately interpret their child's signals, and respond appropriately (Ainsworth et al., 1978).

In comparison, parental experience of general anxiety/depression but not fear was related to less frequent child coping behavior (i.e., playing, non-procedural talk) through less frequent coping-promoting behavior (i.e., distraction). Reductions in positive parenting behavior have been found previously (Lovejoy, Graczyk, O'Hare, & Neuman, 2000), although not consistently (Hudson & Rapee, 2001; Lovejoy et al., 2000). Further research is required to replicate and investigate why a child's burn dressing change prompted this particular parenting behavior. Interestingly, parental pre-procedural fear trended but did not significantly reduce child coping behavior through reduced coping-promoting behavior. Null effects of parental fear have been found previously (Dahlquist et al., 1994; Frank, Blount, Smith, Manimala, & Martin, 1995), although this is in contrast to the wider literature (Bearden et al., 2012; Bernard & Cohen, 2006; Jacobsen et al., 1990; Jay et al., 1983). A key difference between research designs may be that our study limited data collection to observing the *first* dressing change. A recent study found procedural distress predicted later procedural coping through parental worry (Campbell, DiLorenzo, et al., 2017), indicating that parents can learn anticipatory procedural anxiety. In the current study it is possible parents did not know what to expect, and therefore pre-procedural anxiety did not drive behavior during this dressing change. An updated version of Brown's model pertaining to burn wound care is presented in Figure 4.2.

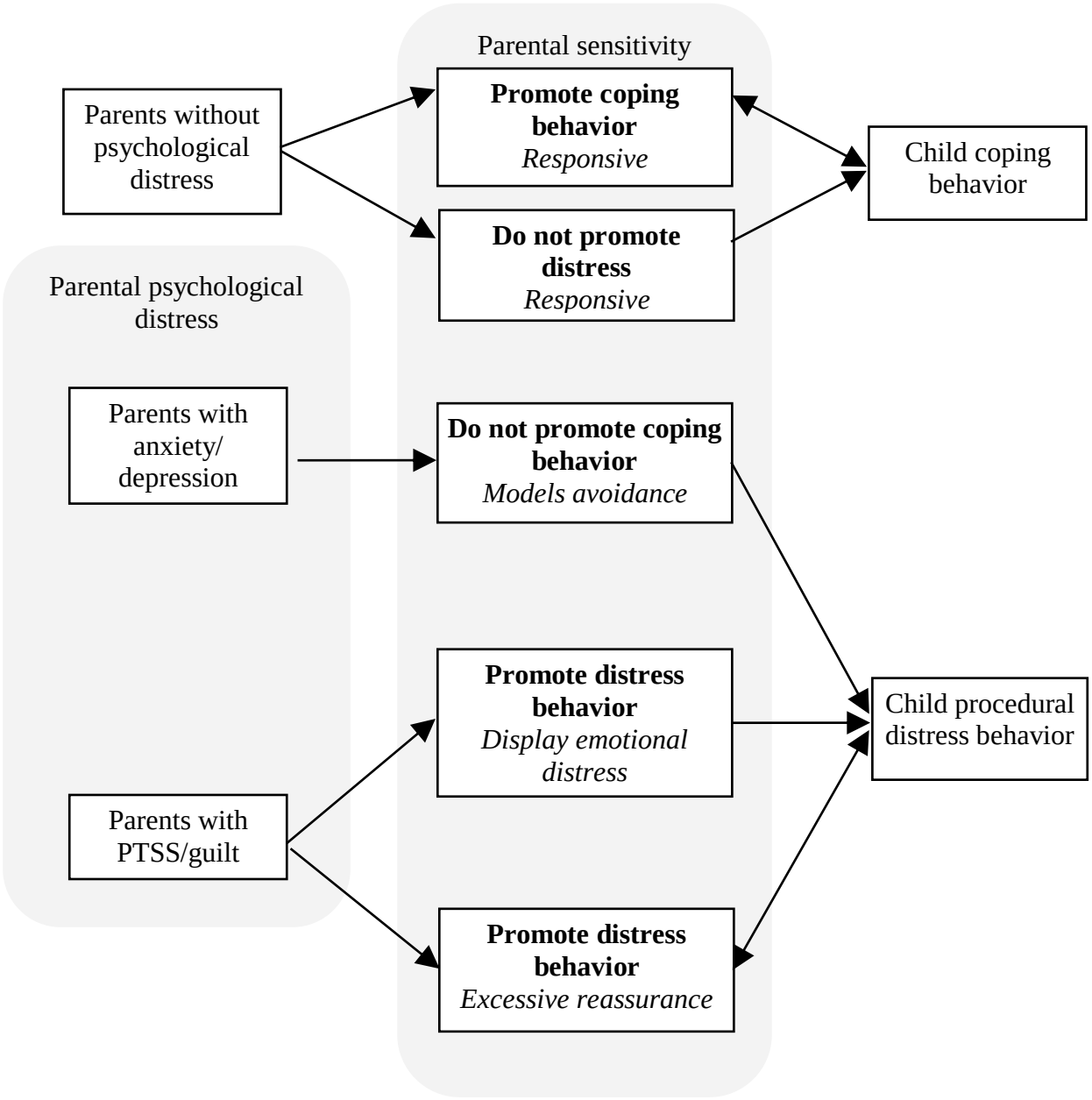


Figure 4.2 Updated model of parental acute psychological stress and behaviors as relating to child coping and distress behavior during pediatric burn wound care

This study possesses a number of strengths. The research tested a theoretical model and was the first to investigate the effect of parental acute psychological distress and parenting behavior on child behavior during burn wound care. The study took a unique trauma-focused approach by assessing the influence of parental psychological distress from the burn injury, on the child's behavior during the first burn dressing change. Moreover, the study sampled young children including 1–2-year-olds who are typically omitted from research because they are preverbal (Blount et al., 1997), yet are recognized as being at greatest risk for both burn injury (Stockton et al., 2015) and procedural distress (Young, 2005). Previous research has validated the use of the B-CAMPIS as representative of child procedural pain/fear during burn wound care using parent- and nurse-reports (see Chapter 3). Therefore, associations can be drawn regarding the parent's influence on child procedural pain/fear.

It is important to contextualize these results within the context of receiving pharmacological intervention. While the administered amounts were standardized and based on clinical experience, variations in adequacy could have remained. Furthermore, the use of pharmacological intervention is designed to induce behavioral changes (i.e., sedation), but distress behavior is not a side-effect of the drugs utilized. Distress behavior was still observed in this sample, which indicates the presence of pain when self-report is not possible for the majority of the sample (von Baeyer & Spagrud, 2007). Future research might investigate the interplay between pharmacological and non-pharmacological intervention modalities on child distress behavior.

Mention must also be made regarding the availability of some non-pharmacological interventions in the burns center. That is, some children (and their parents) were exposed to distraction interventions such as television, the Ditto™ device, and the presence of clown doctors. The use of these may have reduced the level of distress in the sample and/or influenced parental behavior. However, there was no formalized instruction to parents to engage with available distractors and the Ditto™ is only suitable for children 4 years and older. Therefore, it is likely that explicit encouragement for parents to use distraction techniques to support their child would be valuable.

It is a limitation that child traumatic stress was not analyzed, as it is indicated by behavioral changes after a trauma (Scheeringa & Haslett, 2010), and the re-exposure to the burn pain is likely to contribute to behavioral distress during dressing changes. In addition, the current analysis did not take into account behavior of additional present family members or healthcare professionals. Healthcare professional behavior mirrors parent behavior (Cohen et al., 2005), although it is not as influential as parents for predicting child distress (Racine, Pillai Riddell, Flora, et al., 2016). It must

also be noted that the models produced small effects. Small effects indicate that other factors may be impacting child behavior, such as injury severity and adequacy of pharmacological intervention. Finally, parent and child behavior was not sequentially analyzed to provide evidence of directional influence. While parent and child behavior is likely bi-directional in nature (Chapter 1, published as E. A. Brown et al., 2018b), it is important to note that identifying the unique influence of parental psychological distress gives some evidence of direction from parent to child, rather than child to parent. That is, an alternative mediation model of parental psychological distress influencing parental behavior through changes in child behavior is not logical. Further research may consider the impact of parental psychological distress on the sequential nature of parent-child behavior.

The results of this study provide directions for future research. Findings should be replicated, ideally at an alternate site, in order to further understand the interactions between psychological distress and behavior in this population. Research should consider the potential long-term consequences of parental acute psychological distress and procedural behavior on a child's recovery following a burn injury. The current findings indicate an early targeted intervention to address parental acute psychological distress and parenting behavior can be of benefit to reduce child procedural distress during burn wound care. Supporting parents with additional psychological and behavioral instruction may reduce the likelihood of burn wound care becoming additional traumatic events for the children and their parents. Research has not attempted to coach parenting behavior during young child burn wound care before. Future research will need to evaluate the effect of a targeted intervention on pediatric procedural distress during burn wound care.

The results of the study have direct application for pediatric burn centers. In general, the study demonstrates the value of involving parents in pediatric wound care for managing child distress. However, the study does indicate that parents who are distressed will require additional support for their presence to be beneficial. Guidelines for pediatric burn wound care recommend parents be present (Beerthuizen et al., 2017), and research indicates parents prefer to be present (Egberts et al. 2018). Therefore, the authors suggest that it is important to consider how to best equip parents, especially those showing signs of distress, so that they can use positive coping strategies to support their child during wound care. Another application is that clinicians can be aware that even parents presenting for a "small" burn can potentially have quite strong acute distress reactions. When a parent does display distress, clinicians can be sensitive to them (i.e., normalize their reactions), as well as prompt the parent to engage in coping-promoting behaviors, as appropriate.

In summary, this study is the first to test the relationship between parental acute psychological distress and young child behavior during the first burn dressing change. Findings indicate additional psychological distress in parents reduces child coping and increases child distress, through negative differences in parenting behavior.

Chapter 5. The role of parental acute psychological distress in paediatric burn re-epithelialisation

5.1 Contribution to authorship

The design of this study was shared between myself (80%) and my supervisors. I collected the data (100%). I am responsible for the statistical analyses (100%) and interpretation of the results (100%). I am responsible for writing the paper (100%), which my supervisors provided detailed feedback.

5.2 Preamble

As identified in Chapter 1, psychological stress has been previously associated with delayed wound healing. The findings of Chapter 3 indicate acute parental psychological distress influences child procedural distress. Procedural pain has previously been linked with pediatric burns re-epithelialisation, however research has not previously examined the influence of parental stress on pediatric re-epithelialisation. This chapter presented a model of pediatric burn re-epithelialisation and empirically tested influence of parent and child procedural distress in relation to the child's rate of re-epithelialisation. This chapter is under review for publication at a health psychology journal.

5.3 Introduction

The majority of young child (under 5-years-old) accidental burns occur in the home under the supervision of the primary caregiver, such as knocking over a hot cup of tea in the kitchen or turning on the hot water tap in the bathroom (Burgess, Kimble, Watt, & Cameron, 2017; Stockton et al., 2015). Children often experience pain and psychological distress from the burn injury itself, as well as the prescribed wound care (Pardesi & Fuzaylov, 2017). Young children are particularly at risk of procedural pain and fear/anxiety, due to underdeveloped cognitive abilities (E. A. Brown et al., 2018b). In general, stress is related to delayed wound healing (for a review, see Walburn et al., 2009). Investigated measures of stress include negative psychological states (i.e., anxiety, depression, posttraumatic stress), stressful conditions (i.e., academic examination), or stressful experiences (i.e., negative pain appraisal). This association is important for burns because timely re-epithelialisation (i.e., less than 21 days for skin to close over the wound) reduces the likelihood of hypertrophic scarring (Cubison, Pape, & Parkhouse, 2006; Deitch, Wheelahan, Rose, Clothier, & Cotter, 1983; Hassan, Reynolds, Clarkson, & Brooks, 2014; Lonie, Baker, & Teixeira, 2017). Each additional day during the first 3 weeks before re-epithelialisation has been shown to increase the likelihood of scarring (Finlay et al., 2017). There is support to test the potentially negative impact of stressful burn wound care on time to wound re-epithelialisation (Upton & Andrews, 2014). Understanding individual and inter-personal risk factors that increase time to re-epithelialisation following a child's burn is important to improve recovery outcomes.

Psychological distress is thought to influence wound healing through physiological and/or behavioural changes (Robinson, Norton, Jarrett, & Broadbent, 2017; Wisely, Wilson, Duncan, & Tarrier, 2010). Stress influences physiology through increased hormone release (i.e., cortisol and catecholamines), which changes cellular trafficking, proliferation, antibody production and cytokine secretion (Dentino et al., 1999; Godbout & Glaser, 2006; Lutgendorf et al., 1999; A. H. Miller, 1998; Padgett & Glaser, 2003). In addition, it has been proposed that stress influences health behaviours (i.e., sleep patterns, diet, drug consumption, exercise, and adherence to medical treatment) that can delay the physiological process of healing (Robinson et al., 2017).

Perceived pain severity also delays wound healing through physiological and behavioural changes. Pain severity influences physical healing through nociceptor hyper-sensitisation and hyper-inflammatory cellular and extracellular matrix changes (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002; Widgerow & Kalaria, 2012). Pain can also lead to avoidance behaviours which is thought to contribute to chronic wounds (Roaldsen, Elfving, Stanghelle, Talme, & Mattsson, 2009).

Pain and stress are also thought to influence each other (Sharp & Harvey, 2001; Wallace, 1985). The research has focused on general pain as a predictor of delayed healing, however procedural pain has also been identified as a contributor. Within burn cohorts, two paediatric studies found procedural pain had a significant negative relationship to re-epithelialisation time (N. J. Brown, Kimble, Gramotnev, et al., 2014; K. Miller et al., 2011). While these studies did not test the relationship mechanism, N. J. Brown, Kimble, Gramotnev, et al. (2014) demonstrated the relationship was eliminated with the use of a nonpharmacological procedural pain intervention. Considering procedural pain is predictive of a future reduced pain threshold (increased pain sensitivity) (Taddio et al., 1995; Taddio et al., 1997), it is possible that procedural pain delays wound healing through increasing general wound pain. These relationships are modelled in Figure 5.1.1. For young children who are often preverbal and have limited cognitive reasoning skills, procedural pain and fear are commonly identified through distress or non-compliant behaviour (for a review, see Young, 2005). In this case, observed and proxy-reported measures of procedural pain and fear should be tested in relation to burn wound re-epithelialisation.

In addition to procedural pain, parental acute psychological distress may also influence time required for a child's would to re-epithelialise. It is common for parents to experience psychological distress, including anxiety, guilt, and posttraumatic stress symptoms (PTSS) following a paediatric burn injury (Bakker et al., 2012; Stoddard, Saxe, et al., 2006). Parental anxiety and PTSS have been found to influence child procedural coping and distress behaviours through reduced parental coping-promoting and increased distress-promoting behaviours (E. A. Brown et al., 2019). Largely, parental behaviour during paediatric medical procedures has been related to child procedural coping and distress, and child procedural pain and fear (for a review, see E. A. Brown et al., 2018b). Given the previously identified role pain plays in wound healing, there is a potential cascade of parental acute psychological distress influencing child re-epithelialisation through parenting behaviour influencing child pain severity. Parental behaviour at the first burn dressing change may represent an ongoing pattern during the repeated dressing changes, which would contribute to the child's cumulative experience of procedural pain and fear during the re-epithelialisation period. Therefore, parental procedural behaviour might influence child re-epithelialisation, and be an avenue of intervention.

It is also possible that parental acute psychological distress affects the child's re-epithelialisation in addition to through its' indirect effect on parental procedural behaviour. Parental acute psychological distress contributes to child psychological distress following a child's burn (De Young et al., 2014; Landolt et al., 2012), which may influence the child's time to re-

epithelialisation. These relationships in relation to previously identified mechanisms of wound healing have been modelled in Figure 5.1.2. Notably, different parental acute psychological distress presentations (general anxiety/depression symptoms compared to PTSS/guilt) appear related to different parental procedural behaviours (E. A. Brown et al., 2019). The divergence suggests it is prudent to test the range of parental acute psychological distress presentations individually.

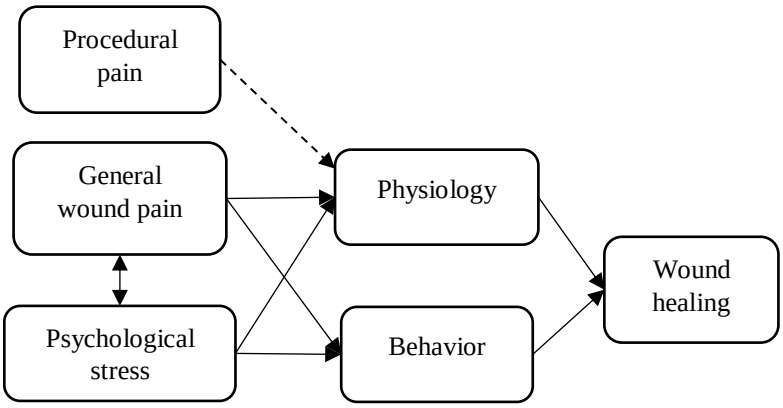


Figure 5.1.1. Pre-existing evidence of mechanisms of the stress-wound healing relationship

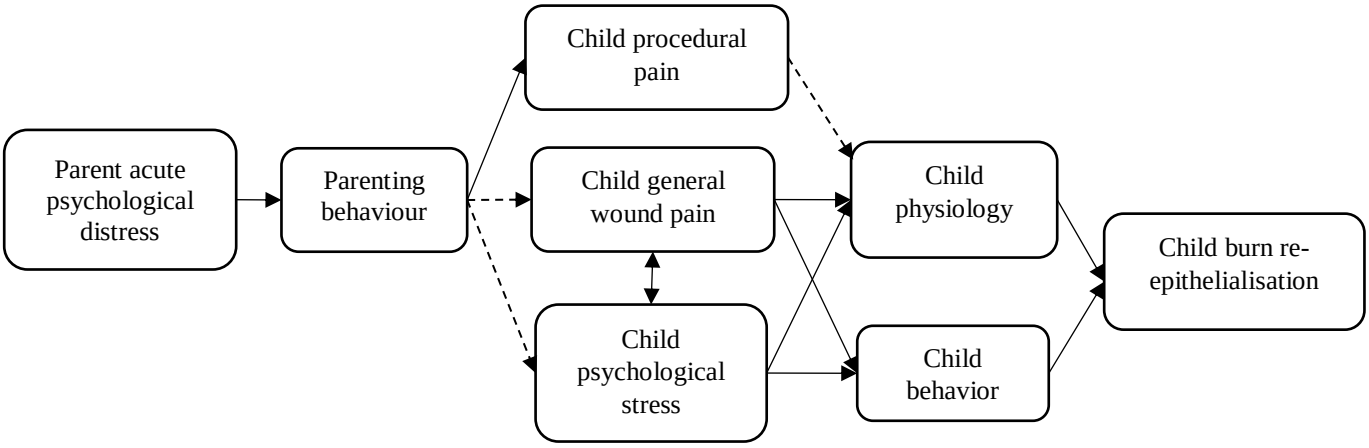


Figure 5.1.2. Hypothesised parent-child relationship for child burn re-epithelialisation time.

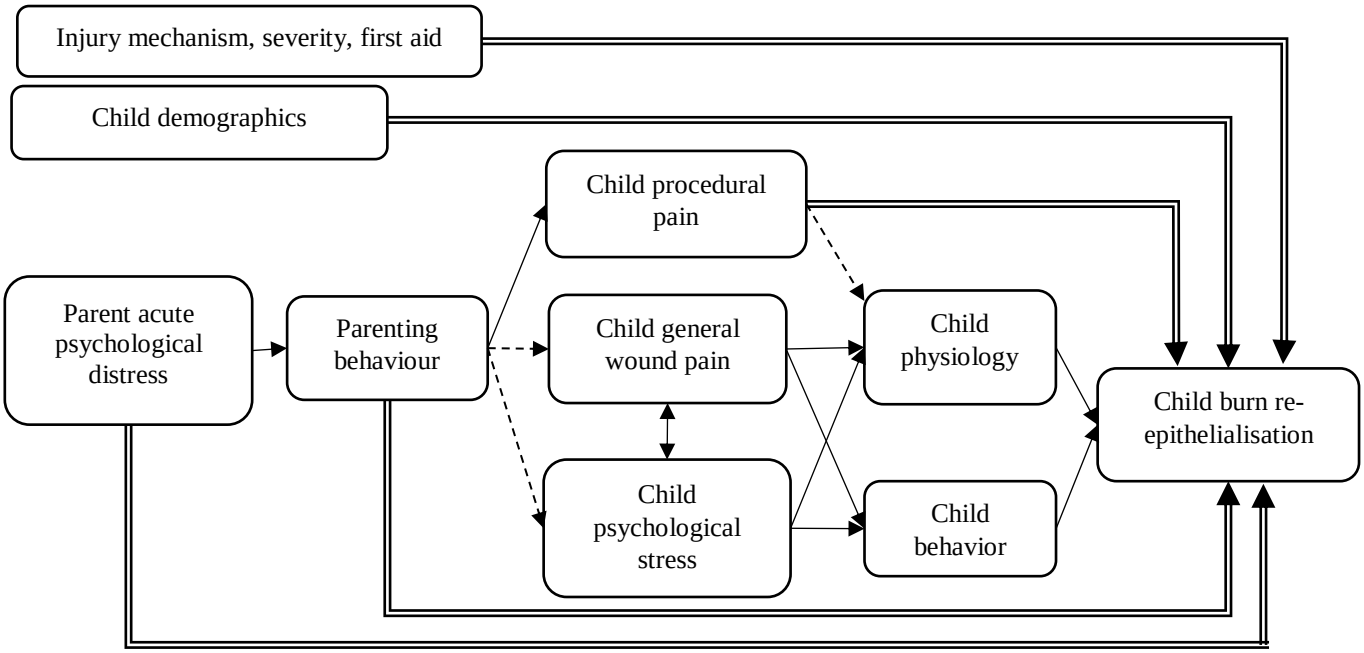


Figure 5.1.3. Relationships tested in the current analysis, including potential control variables.

Figure 5.1 Model development of the role of parental psychological distress behaviour in paediatric burn re-epithelialisation

Note. Dotted lines indicate the hypothesised association, single solid lines indicate pre-existing evidence, double solid lines indicate associations tested in the current analysis.

The current study seeks to test the potential relationship between parental acute psychological distress and parental procedural distress behaviour on child burn wound re-epithelialisation. As part of a larger observational study, the current analysis does not include all of the previously identified mechanisms for predicting burn wound healing. Specifically, data on the child's general wound pain, psychological distress, physiology, and post-injury behaviour was not gathered. Therefore, although a complex mediational model is put forth, the current analysis is constrained to testing only part of the overall model, that is the direct relationships between parental acute psychological distress, parental procedural behaviour, and child procedural pain, on time to re-epithelialisation.

To reduce the likelihood of the parent-related variables accounting for variance relating to an alternative predictor, known injury-related predictors of burn re-epithelialisation will be tested for inclusion as control variables. These variables include burn severity (depth and size), burn mechanism (flame), delayed presentation to a burns centre, and appropriate first aid (N. J. Brown, Kimble, Gramotnev, et al., 2014; Cuttle et al., 2008; Cuttle, Kravchuk, Wallis, & Kimble, 2009). As injury-related variables likely have the strongest association to re-epithelialisation time, these will be entered in the model first. Child procedural distress variables likely have the second strongest associations to re-epithelialisation time, as they represent procedural pain as an established predictor. Family demographics will also be considered here. Finally, parental acute psychological distress and parental procedural behaviour variables will be entered into the model, to assess over and above injury and child procedural distress variance. How the current analysis variables fit in the previously discussed model is depicted in Figure 5.1.3.

The role of parental acute psychological distress has not previously been investigated in relation to paediatric wound re-epithelialisation time. The aim of this study is to test to role of parental acute psychological distress and parental procedural behaviour on paediatric burn wound re-epithelialisation. The child age range of 1–6-years-old was chosen to reflect the ages a child is most likely to sustain a burn injury at home (Stockton et al., 2015) and during a time that children are particularly reliant on their parents to help them to recover physically and emotionally after an injury. It was hypothesised that parental acute psychological distress variables (PTSS, general anxiety/depression symptoms, pre-procedural fear, and/or guilt) and/or parenting behaviour during the wound care would influence the child's time to re-epithelialise, after controlling for relevant injury, demographic, and child procedural distress variables.

5.4 Methods

5.4.1 Participants and Design

Participants were recruited as part of a larger observational study of 87 parent-child dyads investigating parental acute psychological distress and parent-child behaviour during burn wound care (E. A. Brown et al., 2019). Four children were excluded from the present analysis because they required grafting (therefore wound re-epithelialisation could not be estimated). Therefore, data from 83 families from this data set (95%) were analysed for the research questions in this study. All children were treated with silver dressings as per the protocol of the treating unit, Pegg Leditschke Children's Burns Centre (Gee Kee, Kimble, Cuttle, Khan, & Stockton, 2015; Gee Kee, Stockton, Kimble, Cuttle, & McPhail, 2017).

Parents of children aged 1–6-years-old were recruited at their first burns dressing change, following an unintentional burn injury. Oral premedication was administered to all children and commonly consisted of a combination of oxycodone and paracetamol, with the possibility of ibuprofen, midazolam and/or fentanyl. The range of premedication was based on the treating nurse's clinical judgement of anticipated pain based on previous photos and descriptions of the wound. Weight-appropriate quantities of the premedication were approved by a doctor. Families were excluded from participating in the study if (1) the child had a developmental disorder (e.g., autistic spectrum disorder) or (2) a comorbid head injury (Glasgow Coma Scale < 12), (3) the child's injury was from suspected abuse or neglect, (4) the primary caregiver was not present for the wound care, or (5) the parent's level of English was insufficient for completing questionnaires and verbal coding. Children with a developmental disorder were excluded because their response to wound care and their relationship with their parents may not represent the experience for the majority of young children undergoing burn wound care.

The University of Queensland Human Research Ethics (2015000623) and the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC/15/QRCH/27) approved this study. Written informed consent was obtained from parents, however, all children were under the age of 7-years-old and therefore not required to give assent.

5.4.2 Measures

Injury and sample characteristics

Injury and sample characteristics have been reported in Chapter 3. In brief, parents completed a questionnaire regarding family demographic information (parent and child genders, ages, ethnic backgrounds, annual household income), and the child's medical history (number of previous hospital admissions). Parental socio-economic status was estimated based on the suburb of the family's primary residence, using the Socio-economic Indexes for Australia (SEIFA) Qld Education Ranking in the 2016 Postcode Index of Education and Occupation tables (Australian Bureau of Statistics, 2018). The SEIFA ranks suburbs in Australia relative to advantage and disadvantage according to the recent Census data. Injury data (injury location, injury mechanism, wound depth, percentage of total body surface area burned [%TBSA], delivery of first aid) was attained from medical records. The attending consultant or registrar (N=14) recorded their clinical judgement regarding the burn wound depth and %TBSA at the child's first dressing change as per clinical practice. First dressing change data (number of pharmacological interventions utilised) was recorded at recruitment.

Wound re-epithelialisation

Number of days until re-epithelialisation was estimated as the number of days from injury until outpatient clinic discharge. This was identified from medical charts. Usual care required the child to return to the clinic for a dressing change every 3–7-days until the consultant observed full re-epithelialisation. If the burn re-epithelialises in less than 17 days, the child is likely to be discharged, otherwise the child is referred to scar management at time of re-epithelialisation.

Parents were not asked to change the dressing at home. However, parents were asked to protect the dressing by ensuring the child did not submerge it in water or play in sand or dirt. If the nurse secured a tube to the dressing, parents were also instructed to keep the dressing moist by injecting a small amount of water into the tube 3 times per day until they presented for the next dressing change. This is not a painful event.

In three instances, families did not present for subsequent burn wound care appointments, in which case re-epithelialisation was assumed to occur 7 days after the first dressing change (that is, at day of their subsequent appointment). This estimation was highly likely as the three children had sustained small wounds (superficial-partial depths, <1% total body surface

areas). Re-epithelialisation has been estimated in a similar fashion previously (K. Miller et al., 2011).

Parent-reported child measures

Procedural pain. Parents rated their child's pre-, peak-, and post-procedural pain on the Numerical Pain Rating Scale (Downie et al., 1978). The single item asked parents to report the "worst pain your child has experienced during this medical treatment" on an 11-point scale. The scale is anchored with *no pain* on the left and *worst imaginable pain* on the right. Studies have identified optimal cut-off points for pain interference, suggesting scores of 0 (no pain), 1–3 (mild pain), 4–6 or 4–7 (moderate pain), and 7–10 or 8–10 (severe pain) (Oldenmenger, de Raaf, de Klerk, & van der Rijt, 2013).

Procedural fear. Parents reported their child's fear on the Visual Analogue Scale-Anxiety (VAS-A) (Choiniere et al., 1989). The VAS-A consists of a continuous line wherein the left anchor is labelled *no anxiety or fear* and the right anchor is labelled *worst possible anxiety or fear*. The VAS-A has been used as a proxy for child fear during medical procedures (Bringuier et al., 2009). Parent-reported child fear has been validated to child self-reported fear (Bringuier et al., 2009).

Nurse-reported child measures

Pain-related distress behavior. The administering nurse reported the child's pre-, peak-, and post-procedural pain-related distress behaviour on the Faces, Legs, Arms, Consolability, Cry (FLACC) (Merkel et al., 1997). A total observational score for behaviour calculated based on scores relating to the child's face, legs, arms, consolability, and cry. Each subscale can score 0-2, for a total score of 0–10 (0 represents no distress, 10 represents highest distress possible). The FLACC has excellent responsiveness, reliability, and validity (von Baeyer & Spagrud, 2007), and has been recommended for nurse-reporting of young child behavioural distress across a range of hospital procedures (Manworren & Hynan, 2003).

Parent measures

A range of acute parental psychological distress measures were utilized in this analysis. These include the PC-PTSD screen (measuring PTSS), the GGS (measuring guilt), the VAS-A (measuring fear), and the PHQ-4 (measuring symptoms of anxiety and depression). These measures demonstrate good psychometrics and are appropriate for this sample. A detailed description of these measures is reported in Chapter 4.

Behavioral coding

Burns-Child Adult Medical Procedure Interaction Scale (B-CAMPIS) (E. A. Brown et al., 2018a) was used for observed parent-child behaviour. The B-CAMPIS provides overall scores for child behaviour (coping and distress) and parent behaviour (coping-promoting and distress-promoting). The B-CAMPIS measures frequency of specific nonverbal and verbal behaviours, and proportions are calculated based on the length of the procedure. The B-CAMPIS coding scheme was specifically validated for use in young child burn dressing changes (E. A. Brown et al., 2018a). A combination of live coding of nonverbal behaviour and audio recording for later coding of verbal behaviour was completed by the primary researcher. A second observer coded approximately 20% of families to check inter-coder reliability. E. A. Brown et al. (2018a)The B-CAMPIS is a reliable measure, with inter-coder ratings of agreement for individual codes on a subset ranging from good to excellent (average child distress ICC=.89, average child coping ICC=.88, average parent distress-promoting ICC=.84, average parent coping-promoting ICC=.89). Convergent and incremental validity has been established for the B-CAMPIS (E. A. Brown et al., 2018a).

5.4.3 Procedure

Potential participants were recruited at their first presentation to the Pegg Leditschke Children's Burns Centre, Queensland Children's Hospital, Brisbane, Australia. Parents completed questionnaires about of demographic information and acute psychological distress for themselves, and reported their child's current pain and fear levels before their child's first dressing change. Parent and child behaviours were coded from the time the nurse began to remove the dressing, until 2 minutes after debridement (the washing and cleaning of the wound), unless the child left the room earlier. Following coding, the coder asked the parent to retrospectively report the child's peak- and post-procedural pain and fear (and their own peak procedural and post-procedural fear). At the same time, the coder asked the nurse to retrospectively report the child's pain-related distress behaviour (pre-, peak, and post-procedure). Specifically, the nurse recorded the child's pre-procedural FLACC prior to dressing removal commencing, however, the nurse recorded the child's peak and post-procedural FLACC scores at the conclusion of the child's treatment. It is standard practice for the nurses at this center to record pre-, peak, and post-procedural FLACC scores for every patient.

5.4.4 Statistical Analyses

A review of randomized controlled trials assessing the effect of stress on wound healing (Robinson et al., 2017) reported 20 studies, of which the average effect size was in the medium range (d=.74). The two paediatric burn samples included in the review also had medium effect sizes (N. J. Brown, Kimble, Gramotnev, et al., 2014; K. Miller et al., 2011). Sample size for the R2 increase by parental distress in a linear multiple regression was calculated using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009). Sample size was calculated using a medium effect size (f^2=.15) for a maximum of 3 parent-related variables, an upper limit of 10 total predictors (to allow for expected injury- and child-related predictor variables), with an α=.05, and 1–β=.80. For the current study, a sample size of 78 participants was estimated.

To eliminate alternative explanations of the analyses, a number of potential predictor variables were tested for univariate association with days to re-epithelialisation, using a conservative cut-off of p<.1 (see

Table 5.1 for a complete list). Significant univariate variables were assessed for multi-collinearity using Pearson's bivariate correlation analyses. The hierarchical linear regression model was developed using forward selection, starting with demographic and injury variables at Block 1. Child procedural pain variables (Block 2) and parent acute psychological distress/procedural behaviour variables (Block 3) were entered hierarchically (i.e., beginning with the variables that demonstrated the strongest associations with wound re-epithelialisation). The utility of each new variable was tested using the *F*-test for ΔR^2 before subsequent variables were added. Listwise deletion was employed for consistency during model building.

Table 5.1 List of potential predictor variables

Injury	Wound depth
	%TBSA
	Injury mechanism
	Burn location
	Adequate first aid
First dressing change	Procedure duration
	Polypharmacy
Child demographics	Age
	Sex
	Ethnicity
Parent demographics	Sex
	Age
	SEIFA
	Annual income
Child procedural distress	Pre-, peak-, post-procedural pain (P)
	Pre-, peak-, post-procedural fear (P)
	Pre-, peak-, post-procedural pain (N)
	Coping behaviour (O)
	Distress behaviour (O)
Parent acute psychological distress	Pre-procedural fear (P)
	General anxiety/depression symptoms (P)
	Guilt (P)
	PTSS (P)
Parent procedural behaviour	Coping-promoting behaviour (O)
	Distress-promoting behaviour (O)

SEIFA=Socio-economic Indexes for Australia; %TBSA=Percentage of total body surface area; B-CAMPIS=Burns-Child Adult Medical Procedure Interaction Scale; PTSS=Posttraumatic stress symptoms. (P)=parent-reported; (N)=nurse-reported; (O)=observer-reported.

5.5 Results

5.5.1 Preliminary analyses

The days to re-epithelialisation range was 3–35 days (*M*=11.71, *SD*=6.42). Sixty-two (74.7%) children re-epithelialised within 2 weeks of injury, 13 (15.7%) children re-epithelialised between 2–3 weeks of injury, and 8 (9.6%) children took longer than 3 weeks (21 days) for re-epithelialisation. Twelve children (14.5%) underwent scar management as a result of clinical referral. A summary of the demographics and proportions of participants reporting above clinical measure thresholds are reported in Table 5.2 and Table 5.3.

All variables of interest were assessed for non-normality, and were within acceptable ranges. Univariate analyses revealed 4 injury- and child-related variables (wound depth, %TBSA, SEIFA, parent-reported peak-procedural pain), and 2 parent-related variables (PTSS and guilt) were individually associated with days to re-epithelialisation (see Table 5.4). Correlational analyses of these variables indicated multi-collinearity was not present.

Missing data was observed on the parent-reported peak-procedural pain, parental guilt, and parental PTSS measures. Parent-reported peak-procedural pain is a single-item measure, therefore listwise deletion was employed. Two participants had responded to 3 of the 4 items on the PTSS, therefore, the participant mean was substituted for the fourth item. A small number of participants did not respond to any items on the parental guilt (*n*=6) and parental PTSS (*n*=4) measures, therefore, listwise deletion was employed.

Table 5.2 Demographics

Demographics (*N*=83)	*n* (%)	Mean±*SD* (range)
Child age, years		2.95±1.74 (1.04–6.94)
1-year-old	32 (39)	
2-years-old	22 (27)	
3-years-old	8 (10)	
4-years-old	4 (5)	
5-years-old	11 (13)	
6-years-old	6 (7)	
Child sex		
Male	47 (57)	
Female	36 (43)	
Child ethnicity		
Anglo/European	56 (78)	
Pacific Islander	8 (11)	
Asian	5 (7)	
African	2 (3)	
Aboriginal/Torres Strait Islander	1 (1)	
Not stated	11 (13)	
Parent age, years, *n*=75		32.44±5.43 (21–43)
Parent sex		
Mothers	69 (83)	
Fathers	14 (17)	
Parent education		
High school education or less	19 (28)	
Technical training	18 (26)	
University degree	32 (46)	
Not stated	14 (17)	
Annual family income, $AUD		
Less than $40,000	7 (11)	
$40,000-80,000	19 (29)	

Demographics (*N*=83)	*n* (%)	Mean±*SD* (range)
$80,000-120,000	20 (31)	
More than $120,000	21 (29)	
Not stated	18 (22)	
SEIFA Decile groups		
Lowest deciles (1–3)	28 (34)	
Medium deciles (4–7)	20 (24)	
Highest deciles (8–10)	35 (42)	
Burn depth		
Superficial-partial	63 (76)	
Deep-partial	18 (22)	
Full-thickness	2 (2)	
Burn %TBSA		1.85±2.14 (0.50–12.00)
Injury mechanism		
Scald	40 (48)	
Contact	41 (49)	
Friction	1 (1)	
Radiant Heat (sunburn)	1 (1)	
Number of days after injury at first dressing change		3.27±0.99 (1–6)
Dressing change duration, min:sec		7:13±3:37 (5:57–23:25)
Number of pharmacological intervention		1.94±0.60 (1–3)

SD=Standard deviation; SEIFA= Socio-economic Indexes for Australia Qld Education Ranking; PTSS=Posttraumatic Stress Symptoms.

Table 5.3 Clinical Characteristics

Clinical Characteristics (*N*=83)	*n* (%)	Mean±*SD* (range)
Child coping behaviour (O)†		2.55±1.91 (0–8.74)
Child distress behaviour (O)†		3.96±4.04 (0–19.93)
Child pre-procedural fear (P), *n*=80		1.75±2.15 (0–8.4)
Child pre-procedural pain (P)		1.87±2.03 (0–9)
None (0)	29 (35)	
Mild (1–3)	38 (46)	
Moderate (4–7)	15 (18)	
Severe (8–10)	1 (1)	
Child pre-procedural pain (N)		0.1±0.43 (0–3)
Child peak-procedural fear (P), *n*=75		3.9±3.56 (0–10)
Child peak-procedural pain (P), *n*=81		4.63±3.18 (0–10)
None (0)	12 (15)	
Mild (1–3)	22 (27)	
Moderate (4–7)	27 (33)	
Severe (8–10)	20 (25)	
Child peak-procedural pain (N)		2.77±2.30 (0–10)
Child post-procedural fear (P), *n*=75		1.07±1.69 (0–7.1)
Child post-procedural pain (P), *n*=82		2.07±2.22 (0–9)
None (0)	29 (35)	
Mild (1–3)	34 (41)	
Moderate (4–7)	17 (21)	
Severe (8–10)	2 (2)	
Child post-procedural pain (N)		0.35±1.1 (0–8)
Parent PTSS, *n*=79, 0–4 potential range		0.92±1.13 (0–4)
No symptoms	39 (49)	
1 symptom	19 (24)	
2 symptoms	11 (14)	
3 symptoms (clinical cut-off)	8 (10)	
4 symptoms	2 (3)	

Parent anxiety/depression symptoms, *n*=74		1.42±2.31 (0–11)
No symptoms (0-2)	60 (81)	
Mild (3–5)	8 (11)	
Moderate (6–8)	5 (7)	
Severe (9–12)	1 (1)	
Parent pre-procedural fear, *n*=77, 0–10 potential range		2.49±2.50 (0–8.6)
Parent guilt, *n*=77, 0–16 potential range		6.55±4.31 (0–16)
Parent coping-promoting behavior (O)†		1.78±1.50 (0–7)
Parent distress-promoting behavior (O)†		2.36±2.63 (0–15)

†Rate of behaviour per minute during wound care assessed by the B-CAMPIS.

(P)=parent-reported; (N)=nurse-reported; (O)=observer-reported.

Table 5.4 Correlation matrix of variables of interest and days to wound re-epithelialisation

	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	18.	19.	20.	21.
1. Days to re-epithelialisation	.47***	.19$^{\wedge}$	-.22*	.14	.15	.03	.13	.25*	.15	.00	.14	-.03	.04	.08	.21$^{\wedge}$	.21$^{\wedge}$	-.09	.17	-.10	.01
2. Wound depth	-	-.05	-.06	.06	-.11	.04	.04	-.03	-.01	.26*	-.03	.06	.00	.05	-.17	-.09	-.27*	-.16	.10	-.04
3. %TBSA		-	-.08	.16	.08	.02	.08	.07	.30**	-.19$^{\wedge}$	.17	-.11	.14	-.05	.24*	.22$^{\wedge}$	.23*	.28*	-.07	.17
4. SEIFA (P)			-	.03	-.10	.11	-.03	-.18	-.15	.01	-.04	.09	-.07	-.12	-.04	.02	-.04	-.16	.12	.06
Child																				
5. Pre-procedural fear (P)				-	.47***	.35**	.21$^{\wedge}$	.10	.20$^{\wedge}$	-.19$^{\wedge}$	.28*	.28*	.32**	.04	.12	.09	.11	.39***	-.14	.07
6. Pre-procedural pain (P)					-	.14	.02	.16	.14	-.19$^{\wedge}$	.18$^{\wedge}$	.10	.33**	.04	.39***	.27*	.23*	.36**	-.21$^{\wedge}$	.06
7. Pre-procedural pain (N)						-	.14	.07	.19$^{\wedge}$	-.11	.39***	.41***	.33**	.19$^{\wedge}$	-.04	-.07	-.07	.11	-.13	.00
8. Peak-procedural fear (P)							-	.55***	.57***	-.42***	.52***	.63***	.21$^{\wedge}$	.07	-.10	.22$^{\wedge}$	-.26*	-.06	-.05	.34**
9. Peak-procedural pain (P)								-	.54***	-.24*	.48***	.36**	.49***	.24*	.20$^{\wedge}$	.39***	-.14	.05	.04	.27*
10. Peak-procedural pain (N)									-	-.42***	.69***	.25*	.30**	.15	.10	.18	-.10	.05	-.03	.40***
11. Coping (O)										-	-.50***	-.18	.03	-.13	-.25*	-.35**	-.14	-.26*	.32**	-.26*
12. Distress (O)											-	.36**	.28*	.25*	.12	.22$^{\wedge}$	.03	.17	-.07	.47***
13. Post-procedural fear (P)												-	.45***	.11	-.15	-.02	-.22$^{\wedge}$	-.13	.19	.30**
14. Post-procedural pain (P)													-	.38***	.04	.11	-.01	.03	.01	.16
15. Post-procedural pain (N)														-	.14	.04	.01	.17	-.19$^{\wedge}$	.04
Parent																				

	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	18.	19.	20.	21.
16. PTSS (P)															-	.56***	.39***	.45***	-.12	.23*
17. Guilt (P)																-	.29*	.30*	-.04	.23*
18. Anxiety/ depression (P)																	-	.44***	-.30**	-.03
19. Pre-procedural fear (P)																		-	-.18	-.01
20. Coping-promoting (O)																			-	.14
21. Distress-promoting (O)																				-

%TBSA=Percentage of total body surface area burned; SEIFA=Socio-economic Indexes for Australia; PTSS=Posttraumatic stress symptoms.

(P)=parent-reported; (N)=nurse-reported; (O)=observer-reported. ***p<.001, **p<.01, *p<.05, ^p<.1.

5.5.2 Hierarchical multiple regression analysis

A hierarchical multiple linear regression was forward built to assess the effects of predictor variables on wound re-epithelialisation. See Table 5.5 for the final model. At Block 1, wound depth and %TBSA accounted for 27% of the variance in re-epithelialisation. After including the injury severity variables, SEIFA did not significantly contribute to the model, and therefore was not included. At Block 2, parent-reported peak-procedural pain accounted for an additional 6% of the variance in re-epithelialisation. At Block 3, parent self-reported PTSS accounted for an additional 6% of the variance in re-epithelialisation. After including parental PTSS, parental guilt did not significantly contribute to the model, and therefore was not included.

The unique effects of parent-reported child peak-procedural pain and parental PTSS can be quantified by interpreting the unstandardized coefficients in the model (Field, 2009). After controlling for injury severity, a one-point increase on parent-reported child peak-procedural pain was associated to a delay in re-epithelialisation of 0.42 days. Furthermore, after controlling for injury severity and parent-reported child peak-procedural pain, a one symptom increase on the PC-PTSD screen was associated to a delay in re-epithelialisation of 1.36 days.

Table 5.5 Hierarchical linear regression model of child and parent variables predicting days to wound re-epithelialisation

Predictor	Model 1 (*N*=78)			Model 2 (*N*=78)			Model 3 (*N*=78)		
	ΔF	ΔR^2	*Final β*	ΔF	ΔR^2	*Final β*	ΔF	ΔR^2	*Final β*
B1. Injury	14.84***	.28		14.84***	.28		14.84***	.28	
%TBSA			.21*			.19*			.14
Wound depth			.50***			.50***			.54***
B2. Child procedural distress				6.79**	.06		6.79*	.06	
Peak-procedural pain (parent-report)						.25*			.20*
B3. Parent acute psychological distress							5.79*	.05	
PTSS									.23*

%TBSA=Percentage of total body surface area; PTSS=Posttraumatic stress symptoms. ***p<.001, **p<.01, *p<.05.

5.6 Discussion

This study was the first to investigate the influence of parental acute psychological distress on paediatric burn wound re-epithelialisation time. The findings suggest acute parental PTSS plays a role in delayed wound re-epithelialisation following paediatric burn injury, and further research should look to confirm and explain this relationship. Parental acute PTSS was associated to delayed re-epithelialisation, after controlling for injury severity and parent-reported child peak-procedural pain. Although parental guilt was univariately associated to re-epithelialisation time, it did not significantly contribute to the statistical model after the inclusion of parental PTSS. Indeed, the variance overlap is not surprising because negative emotion is a part of the DSM-V PTSD diagnosis. Although procedural parental distress-promoting behaviour has been found to mediate the relationship between parental PTSS and child procedural distress (Chapter 4, published as E. A. Brown et al., 2019), the current analyses did not find a direct association between procedural parenting behaviour and child time to re-epithelialise. Parental acute PTSS may instead represent differences in general parenting behaviour.

Distress-related changes in general parenting behaviour may delay the child's re-epithelialisation through three mechanisms: The child's appraisal of general pain, the child's own acute psychological distress, and adherence to home wound care. Firstly, how a parent responds to their child's procedural pain might negatively influence their child's pain appraisal following a burn injury, activating physiological processes such as nociceptor hyper-sensitisation and hyper-inflammatory cellular and extracellular matrix changes that delay re-epithelialisation (Kiecolt-Glaser et al., 2002; Widgerow & Kalaria, 2012). Secondly, altered parenting responsiveness due to their own distress (e.g., becoming withdrawn) might increase the child's acute psychological distress, activating physiological processes that delay re-epithelialisation such as increased hormone release (i.e., cortisol and catecholamines), which changes cellular trafficking, proliferation, antibody production and cytokine secretion (Dentino et al., 1999; Godbout & Glaser, 2006; Lutgendorf et al., 1999; A. H. Miller, 1998; Padgett & Glaser, 2003).

Parental PTSS might also affect their adherence to their child's home wound care. Distress-related non-adherence may occur due to a diminished memory for wound care instructions (Samuelson, 2011). Parents experiencing PTSS may have difficulty remembering instructions to restrict the child from scratching the dressing, playing in sand/dirt, and getting the dressing wet. These behaviours cause a breakdown of the new cells and delay re-epithelialisation. Distress-related non-adherence may also occur if the parent's avoidance symptoms overrides the instruction to inject a small

amount of water into the dressing through a tube 3 times per day. While parents in the current study were not asked to change dressings at home, this may be the practice at other burn centres, and the parent's capacity to do so should be considered.

Further research could investigate general parenting behaviours in relation to the child's pain appraisals, the child's acute psychological distress, and adherence to wound care following a burn. Care should be taken to identify appropriate and accurate measures to assess parenting behaviour, especially post-trauma. Scheeringa et al. (2015) found different effects of parenting behaviour post-trauma depending on the measure. While naturalistic observation would be ideal, the intrusiveness post-trauma may be insensitive to parents of young children (who are often concerned that child safety will become involved). Diary entries may be an alternative way to monitor parental responses to child pain, child psychological distress, dressing care. Another consideration for future research is to plan for a larger sample size to allow modelling of indirect predictors, as depicted in Figure 1b.

A secondary finding was that parent-reported child peak-procedural pain significantly predicted delayed wound re-epithelialisation. Child self-reported peak-procedural pain scores have previously predicted burn wound re-epithelialisation (N. J. Brown, Kimble, Gramotnev, et al., 2014). As we have replicated this result with parents, this suggests that parents reported the young child's pain in a similar manner to child self-reported pain. This is also important as children under 5-years-old have more trouble accurately self-reporting pain intensity, and young child pain can go unrecognised and untreated (Blount et al., 2006; McGrath & Frager, 1996; Shacham & Daut, 1981).

However, it is important to consider the validity of parent-reported measures for child pain. The wider literature demonstrates while parent-report is positively correlated to child self-report, parents of young children tend to underestimate child procedural pain (St-Laurent-Gagnon, Bernard-Bonnin, & Villeneuve, 1999; Zhou, Roberts, & Horgan, 2008). Even so, nurse-reported pain (via FLACC) did not predict wound re-epithelialisation despite doing so previously (N. J. Brown, Kimble, Gramotnev, et al., 2014). Research indicates that clinicians can also under estimate burn pain (Atchison, Guercio, & Monaco, 1986; Geisser, Bingham, & Robinson, 1995; Iafrati, 1986; Perry, 1984; Perry & Heidrich, 1982; van der Does, 1989). When faced with patients who have difficulty accurately self-reporting pain intensity (von Baeyer et al., 2017), a multi-informant approach to assessing young child pain is recommended (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). For burn wound care, it appears helpful for clinicians to consider parental assessment when making decisions regarding pain management.

A series of other potential predictors were hypothesised but not found to be related to burn re-epithelialisation. Specifically, burn mechanism and appropriate first aid did not influence re-epithelialisation. A burn mechanism of flame has previously predicted delayed re-epithelialisation compared to other mechanisms (N. J. Brown, Kimble, Gramotnev, et al., 2014), however, the current study did not recruit any participants with a flame burn injury. This was not an exclusion criterion, most likely because flame burns are not common in paediatric outpatient settings (Stockton et al., 2015). The null effect of appropriate first aid is in contrast to the wider research (i.e., Cuttle et al., 2009). However, the current study's sample size was much smaller (compared to N=459) thereby likely underpowered to see an effect of first aid.

A few limitations of the current research must be noted. The study was designed to focus on the behavioural experiences of parents and their children during the first burn dressing change for several reasons. This design allowed injury-related distress (without cumulative distress from witnessing dressing changes) to be examined. From a clinical perspective, the first burn dressing change is considered to be the most painful. Finally, there was an assumption that behaviours at the first dressing change would be representative of future dressing change behaviours. It is possible that parents and/or children could learn from the first dressing change and modify their procedural behaviour.

Although the measure of wound re-epithelialisation was not as precise as previous studies because 3–7 day dressings rather than daily dressings were used (K. Miller et al., 2011), significant effects were still found. It would not be ethical to increase the wound care to daily dressing changes for greater accuracy of wound re-epithelialisation, given the potential for pain and cumulative procedural and psychological distress from each dressing change. Furthermore, wound size, depth, and re-epithelialisation for each child was estimated by one of 14 burns clinicians across the study period. Although reliability checks were not conducted, we propose that the estimates were accurate, given these clinicians specialise in burn wounds and see approximately 4 new patients every day.

It is a limitation that child PTSS was not assessed. Parental PTSS and child PTSS is often correlated following a paediatric burn injury (De Young et al., 2014; Egberts, van de Schoot, et al., 2018) and it is possible the effect of parental PTSS is indicative of child PTSS. Another avenue to test child stress for re-epithelialisation would have been to include physiological measures such as salivary cortisol or alpha amylase (N. J. Brown, Kimble, Rodger, Ware, McWhinney, et al., 2014). Parents and children can have a shared genetic vulnerability to psychological distress (Drury et al., 2013;

Saxe, Stoddard, Chawla, et al., 2005), which may account for the delay in the physiological healing process. Future work could attempt to replicate these results by directly measuring and testing child and parent psychological and physiological stress. Despite these limitations, the current results provide support for further work to study these mechanisms.

The current study accounted for a total of 40% of variance in re-epithelialisation. This is lower than previous research, even though similar and additional variables were tested, which accounted for 69% of re-epithelialisation (N. J. Brown, Kimble, Gramotnev, et al., 2014). One explanation is that the model of care has progressed to eliminate some of the previously identified predictors (e.g., avoiding delayed presentations by earlier transfer to tertiary care) since 2012. More broadly, predictors of burn re-epithelialisation are still largely debated (Rowan et al., 2015). Several identified predictors include inflammation, infection, nutrition, resuscitation, medical treatment (Rowan et al., 2015). Further research is required to establish a strong criterion (of physiological and psychological variables) to predict time to re-epithelialisation.

Finally, comment must be made regarding the large number of correlational analyses conducted without statistical correction for Type 1 error. The analysis was designed to test the effect of parental acute psychological distress after controlling for all other possible explanations. This led to univariate testing and forward selection in the model building. Even so, it is possible that a 'false-positive' was identified. Future research can look to confirm the null or alternative hypothesis regarding parental acute PTSS as important for timely paediatric burn wound re-epithelialisation.

The findings of this paper indicate acute intervention is likely to be of significant benefit. The low correlation between parental PTSS and peak-procedural pain indicates there are two separate modifiable areas for intervention: parental coping both during wound care and in general following a burn injury. Psychological interventions to reduce stress have been beneficial for wound healing more broadly (for a review, see Robinson et al., 2017). Parent-focused psychoeducation and behavioural modification for improving parental coping during the acute re-epithelialisation period may improve paediatric wound re-epithelialisation. Additionally, further steps can be taken to improve procedural pain management for paediatric burn wound care through a combination of pharmacological and non-pharmacological intervention. Of clinical significance, if time to re-epithelialisation can be reduced (i.e., from 18 to 16 days), the potential for scarring (i.e., patient outcome), as well as need for scar management (i.e., financial cost to health service) can be greatly reduced.

In summary, this is the first study to propose and investigate parental predictors of paediatric burn wound re-epithelialisation. Parents play a very critical yet largely under recognised role in their child's burn wound re-epithelialisation, and the results highlight an important area for further investigation.

Chapter 6. Prevalence and procedural distress as a predictor of psychological impairment of children and their parents at 6 months after a burn injury

6.1 Preamble

The findings of Chapter 5 identified that the parent's acute psychological distress had a negative influence on child wound healing. The review of the literature in Chapter 1 indicated that procedural distress might also have long-term consequences for the child and parent's psychological recovery following an injury. This chapter reported 1) the prevalence of impaired psychological functioning at 6 months for children and their parents, and 2) investigated the influence of procedural distress on 6-month parent and child psychological functioning.

6.2 Introduction

Long-term psychosocial outcomes for children and their parents following pediatric burn injury are commonly reported. This chapter reports the prevalence of psychosocial problems for children and their parents in the current study and investigates procedural distress as a predictor of long-term psychosocial impairment and trauma-affected parenting style. While the majority of children and their parents will not experience ongoing psychosocial problems (Price et al., 2016), a minority can experience short-term psychological distress, long-term psychological distress, or a delayed onset of psychological distress. Of note, monitoring for impairment in young children across a range of psychosocial functioning measures is particularly important because distress can be displayed through a variety of behaviors.

6.2.1 Child outcomes

Research has investigated long-term psychological difficulties in children who have sustained a burn injury (for a review, see Bakker et al., 2013). Commonly researched difficulties include PTSD, internalizing or externalizing behavioral problems, health-related quality of life (HRQL), and chronic pain. PTSD prevalence rates are approximately 25–29% in the acute phase (De Young, Kenardy, & Cobham, 2011; De Young et al., 2012; Stoddard, Saxe, et al., 2006), and 8–19% long-term (De Young et al., 2012; Graf, Schiestl, & Landolt, 2011; Landolt, Buehlmann, Maag, & Schiestl, 2009). Children can also exhibit behavioral problems following a burn injury. Internalizing (De Young et al., 2012; Delgado Pardo, García, Marrero, & Cía, 2008; Liber et al., 2006; Mason & Hillier, 1993a; Meyer et al., 2000) and externalizing problems (Delgado Pardo, Garcia, & Gomez-Cia, 2010; Mason & Hillier, 1993a) have been identified, with approximately 17–37% of children affected (Liber, Faber, Treffers, & Van Loey, 2008; Meyer et al., 1994). Other researched adjustment difficulties for children after a burn injury include lower health-related quality of life (Vollrath & Landolt, 2005) and the presence of chronic pain (Pardesi & Fuzaylov, 2017; Wollgarten-Hadamek et al., 2009; Wollgarten-Hadamek, Hohmeister, Zohsel, Flor, & Hermann, 2011).

6.2.2 Parent outcomes

Parents of children with a burn injury also experience ongoing difficulties with psychological adjustment. Areas that have received research attention include PTSD and parenting stress (for a review, see Bakker et al., 2013). PTSS is highly prevalent with almost half of the parents reporting PTSS during the first months (Hall et al., 2006), and 14–42% still reporting PTSS years afterwards

(Bakker et al., 2010; LeDoux, Meyer, Blakeney, & Herndon, 1998; Rizzone et al., 1994). Alarmingly, up to 1 in 4 parents meet diagnostic criteria for a PTSD diagnosis in the months after their child sustained a burn injury (De Young et al., 2014; Fukunishi, 1998; Hall et al., 2006). Parents can also experience increased parenting stress following a child's injury (Meyer et al., 1994), whereas other research found no increase compared to norms (Blakeney et al., 1998; Blakeney et al., 1993).

6.2.3 Predictors of parent and child psychological impairment

There are personal, social and economic burdens of ongoing psychological distress in children and parents. The presence of PTSS (hyper-arousal, avoidance, intrusions, negative emotion) is inherently unpleasant for the individual and impacts the individual's relationships (Arzi & Dekel, 2000). Furthermore, a PTSD diagnosis in adults has been associated with higher rates of absenteeism, reduced physical health, and increased use of healthcare (Ferry et al., 2015; Hoge, Terhakopian, Castro, Messer, & Engel, 2007). Understanding the predictors of psychological distress is important for designing interventions to ameliorate the distress and, therefore, burden.

A range of predictors of child and parent psychological outcomes following pediatric burn injury have been identified in the literature to date. A summary of the established predictors have been categorized and summarized in Table 6.1. Established predictors were classified as relating to the a) injury, b) wound care procedure/s, c) child or parent demographics, d) child or parent psychological distress, e) family functioning, or f) child procedural distress. A predictor was included if there was a temporal relationship with a child or parent psychological outcome. The table excluded further study information (i.e., child age, injury severity, measures, and time-points), for simplicity. Although some of the variables were not consistently predictive (i.e., injury severity), uniformly non-significant findings were omitted from the table. Of particular interest, some research found variables associated to procedural distress (i.e., in-hospital pain) predicted psychological impairment, which suggests further investigation of procedural distress is required.

Table 6.1 List of significant predictors of child and parent psychological outcomes following a child's burn injury

Predictors	Child			Parent	
	PTSD	Behavioral problems	HRQL	PTSD	Parenting stress
Injury characteristics	%TBSA (De Young et al., 2014; Drake et al., 2006; Graf et al., 2011), burn extent (Saxe, Stoddard, Chawla, et al., 2005; Saxe, Stoddard, Hall, et al., 2005), severity (Haag & Landolt, 2017)		Injury severity (Vollrath & Landolt, 2005)	Burn severity (Bakker et al., 2010; Hall et al., 2006; Rizzone et al., 1994), permanent scarring (Bakker et al., 2010)	
Procedural variables	Length of hospital stay (Drake et al., 2006; Graf et al., 2011), lower morphine dose (Saxe et al., 2001)			Number of invasive procedures (De Young et al., 2014)	
Child demographics	Age (De Young et al., 2014; Saxe, Stoddard, Hall, et al., 2005),		Female sex (Vollrath & Landolt, 2005)		

Predictors	Child PTSD	Behavioral problems	HRQL	Parent PTSD	Parenting stress
Child demographics	Child premorbid problems (De Young et al., 2014), previous life stressors (Saxe, Stoddard, Chawla, et al., 2005), female sex (Meyer et al., 2007; Rivlin & Faragher, 2007)				
Parent demographics		Paternal education (Willebrand et al., 2011)		Parental trauma history (De Young et al., 2014)	
Child psychological distress	Acute PTSS (De Young et al., 2014), separation anxiety (Saxe, Stoddard, Hall, et al., 2005), dissociation (Saxe, Stoddard, Hall, et al., 2005)			Dissociation (Hall et al., 2006)	PTSS (Landolt, Grubenmann, & Meuli, 2002; Liber et al., 2006; Meyer et al., 1994; Rosenberg et al., 2007)

Predictors	Child			Parent	
	PTSD	Behavioral problems	HRQL	PTSD	Parenting stress
Parent psychological distress	Acute distress (Landolt et al., 2012)	Maternal psychological distress (Graf et al., 2011; Liber et al., 2006; Mason & Hillier, 1993b)		Acute distress (anxiety/depression, PTSS) (De Young et al., 2014; Landolt et al., 2012), feelings of guilt (Bakker et al., 2010; Fukunishi, 1998)	
Family functioning	Family relationship (Graf et al., 2011; Stoddard, Saxe, et al., 2006)	Family functioning (Graf et al., 2011)		Family conflict (Hall et al., 2006)	
Child procedural distress-related variables	Elevated heart rate (Stoddard, Saxe, et al., 2006), in-hospital pain (Saxe, Stoddard, Hall, et al., 2005; Stoddard, Saxe, et al., 2006)				

%TBSA=Percentage of total body surface area; PTSS=Posttraumatic stress symptoms; PTSD=posttraumatic stress disorder; HRQL-Health-related quality of life.

Procedural distress as a predictor of psychological impairment

The potentially traumatic experience of burn wound care (i.e., procedural pain and distress) is often implicated as a contributor of long-term child and parent psychosocial problems following pediatric burn injury (De Young et al., 2014; De Young et al., 2012; McGarry et al., 2015). For example, in a qualitative study, parents reported reliving the painful and distressing dressing changes for up to 6 months after treatment (McGarry et al., 2015). Other research reported 18% of parents and 27% of children found dressing changes were the most traumatic part of the burn injury experience (De Young et al., 2014; De Young et al., 2012). Although these figures are related to memory consolidation, they indicate an important area that requires further investigation.

In other populations, procedural pain is predictive of chronic pain (i.e., Fassoulaki, Melemeni, Staikou, Triga, & Sarantopoulos, 2008), and a review recommends reducing procedural pain to limit the development of chronic pain (J. Katz, Clarke, & Seltzer, 2011). In adult burns, a study investigated the effect of wound burn care pain on psychological adjustment 1-month after discharge (Ptacek, Patterson, Montgomery, & Heimbach, 1995). The authors reported higher pain predicted more general psychiatric symptoms, lower HRQL, and more PTSS (moderated by seeking social support). The results indicate that pain relief is critical not only for immediate comfort but also for long-term psychological recovery. Regarding child psychological recovery, research has reported effects of higher pain and elevated heartrate on PTSD development (see Table 6.1). However, to date, burn wound care distress has not been specifically investigated in relation to child and parent psychological outcomes. Understanding the long-term effects will provide further support for reducing procedural distress.

Procedural distress as a predictor of trauma-affected parenting style

Parenting behavior is commonly thought to play a mediating role in child psychological recovery (Drury et al., 2013; Saxe, Stoddard, Chawla, et al., 2005; Scheeringa & Zeanah, 2001). Procedural distress, as a potentially traumatic event, may contribute to a trauma-affected parenting style. For example, a parent who witnesses their child in extreme pain and fear during wound care may modify their parenting behavior to become either overprotective to ensure their child does not require future painful procedures, or avoidant to limit witnessing their child in future painful situations. The effect may be particularly salient for parents of children undergoing burn wound care, due to the frequently repeated nature of wound care. The relationship between procedural distress and long-term parenting behavior has not been investigated in a pediatric burns population.

Consideration of appropriate analysis design is required when investigating parent and child variables over time. As highlighted throughout the thesis, the trauma and recovery is a co-occurring

experience for a child and their parents. In order to consider the dyadic relationship over time, the partner's current state should be accounted for in the analysis. For example, to investigate the influence of a child's procedural distress scores on a parent's long-term psychological functioning, the child's long-term functioning should be utilized as a control variable. Because it is expected that the child's procedural experience will affect both the child's and the parent's 6-month psychological functioning, controlling for the child's 6-month functioning allows investigation of the direct impact of the child's procedural distress on the parent's 6-month functioning. This approach should also be taken for investigating the effect of parental procedural distress on the child's long-term functioning. It should also be noted that the injury, procedural, and demographic variables identified in Table 6.1 should be tested for inclusion in the analyses as potential covariates. Controlling for potentially confounding factors can assist with strengthening the plausibility of findings.

The purpose of this chapter is to report the prevalence of psychosocial functioning of children and their parents at 6 months after a pediatric burn injury, investigate the impact of procedural distress on long-term child and parent psychosocial functioning, and investigate the impact of procedural distress on parenting style. It was hypothesized that 1) a small proportion of children and parents would report psychological problems at 6 months after the burn injury. Furthermore, it was hypothesized that 2) higher parental procedural distress scores at the first burn dressing change would predict higher child psychological impairment after controlling for 6-month parent psychological functioning. Similarly, it was hypothesized that 3) higher child procedural distress at the first burn dressing change would predict higher parent psychological impairment after controlling for 6-month child psychological functioning. Finally, it was hypothesized that 4) higher child procedural distress at the first burn dressing change would be associated with a trauma-affected parenting style after controlling for 6-month child psychological functioning.

6.3 Method

6.3.1 Procedure

At 6 months post-injury, participants (N=87) were contacted by posting out a questionnaire booklet with a return-paid envelope. Participants were reminded via telephone up to three times to return the questionnaires within a 6-week period. The questionnaire included parent-reported child PTSS, behavioral problems, health-related quality of life, and chronic pain measures. Parents also reported their own PTSS, parenting stress, and trauma-affected parenting style. The questionnaire required approximately 20 minutes to complete. On receipt of the questionnaires, a thank you gift of an age-appropriate children's storybook was mailed to participants.

6.3.2 Measures

Some of the measures used in the current analyses have been previously reported. In summary, these measures were collected at the first dressing change and relate to the injury, first dressing change, demographic characteristics, child and parent procedural distress, and parental acute psychological distress. These measures are reported in Table 6.2. The psychometric properties will not be repeated, however, these measures had high reliability and are appropriate for the sample population (see Chapters 3–5).

Table 6.2 List of potential predictor variables for predicting 6-month functioning

Potential control variables	
Injury	Wound depth, %TBSA, injury mechanism, burn location, adequate first aid, days to wound healing
First dressing change	Procedure duration, polypharmacy
Child demographics	Age, sex, ethnicity, behavioral inhibition, number of previous medical admissions
Parent demographics	Sex, age, ethnicity, SEIFA, annual income
Procedural distress variables	
Child	Pre-, peak, and post-procedural pain
	Pre-, peak, and post-procedural fear
	Pre-, peak, and post-procedural pain-related distress behavior
	Coping and distress behavior
Parent	Coping-promoting and distress-promoting behavior
	Pre-procedural fear
Parent injury-related psychological distress	
Parent	General anxiety/depression symptoms, guilt, PTSS

%TBSA=Percentage of Total Body Surface Area burned; SEIFA=Socio-Economic Indexes For Areas; PTSS=Posttraumatic Stress Symptoms.

Child outcomes

PTSS. The Young Child Posttraumatic Checklist (YCPC) is a parent-report 42-item measure that assesses the Diagnostic and Statistical Manual for Mental Disorders 5th Edition (DSM-V) criteria for PTSD in young children (Scheeringa, 2010). Items use a 5-point Likert scale to estimate the presence and frequency of symptoms 0 (*not at all*) to 5 (*every day*). A clinical cutoff score of 26 has been recommended for a probable PTSD diagnosis, and 12 for clinical attention (Scheeringa, 2010).

Emotional and behavioral problems. The Child Behavior Checklist 1.5–5-year-old version (CBCL; Achenbach, 2000) assesses for emotional and/or behavioral difficulties that the child may be experiencing 6 months after the injury. The checklist asks the parent to respond to items about their child's behavior in the past 2 months on a scale from 0 (*not true*) to 2 (*very or often true*). The internalizing and externalizing scales of the CBCL are psychometrically sound (Achenbach & Rescorla, 2000). The CBCL has extensive normative data across clinical and general populations. The borderline clinical cutoff has been reported as a *T*-score of at least 60, and clinical cutoff of at least 65 (Petty et al., 2008). In this study, Cronbach's α was .93.

Health-related quality of life. The Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999) is a 23-item multidimensional health-related quality of life (HRQL) measure, that tests for physical, emotional, social, and school functioning in the child, by parent proxy report. Two versions of the PedsQL were used: The 2–4 for parents of 1–4-year-old children, and the 5–18 for parents of 5–6-year-old children. Parents are asked how much of a problem each item has been during the past 7 days (acute version) with a 5-point Likert scale from 0 (*never a problem*) to 4 (*almost always a problem*). The PedsQL is a reliable and valid measure, with high internal consistencies for the total, physical and psychosocial scales, and distinguishes between healthy and clinical populations (Varni, Seid, & Kurtin, 2001). In this study, Cronbach's α was .79. The current study utilized the cutoff recommendation by Huang et al. (2009) for children with health conditions.

Current pain. The Numerical Pain Rating Scale (NPRS) 11-point scale was used to capture the parent's perception of their child's current pain. The scale is anchored with *no pain* on the left and *worst imaginable pain* on the right. Numeric pain scales are reliable and valid (Downie et al., 1978). Studies have identified optimal cutoff points for pain interference, suggesting scores of 0 (*no pain*), 1–3 (*mild pain*), 4–6 or 4–7 (*moderate pain*), and 7–10 or 8–10 (*severe pain*) (Oldenmenger et al., 2013).

Parent outcomes

Posttraumatic stress symptoms. The Posttraumatic Diagnostic Scale (PDS; Foa, Cashman, Jaycox, & Perry, 1997) is a self-report questionnaire screen for parents with current PTSD diagnosis and

symptomology, based on DSM-IV criteria. The PDS demonstrates excellent internal consistency for total symptom severity and the 3 clusters. The PDS has good stability over time with an 87% agreement rate, α=.74 (Foa et al., 1997). The PDS has also demonstrated validity with the gold-standard Structured Clinical Interview for the DSM-IV (α=.65, 82% agreement), as well as high sensitivity and specificity rates. This study reported the probable diagnosis as well as suggested symptom severity cutoffs indicative of mild (1–10), moderate (11–20), moderate-severe (21–35) and severe (36–51) PTSS (Foa, 1995). Data from all participants who reported a trauma history demonstrated strong internal consistency for each cluster: Intrusions α=.92, avoidance α=.98, and hypervigilance α=.95. Analyses were conducted on the PTSS data from all respondents. Prevalence data was reported for two groups: All respondents, and respondents that indicated the burn as potentially traumatic.

Parenting stress. The Parental Stress Index – Short Form (PSI-SF; Abidin, 1995) is a 36-item measure that uses a 5-point scale to indicate the extent the parent agrees or disagrees with the statement. The PSI-SF is widely used, and reliability and validity are well supported in the literature (Ahern, Ward, Allaire, & Haskett, 2006). Cutoffs for borderline clinically significant parenting stress has been reported at the 85th percentile, and for clinically significant stress at the 91st percentile (Abidin, 1995). In this study, Cronbach's α was .90.

Post-trauma parenting style. The Post-trauma Inventory of Parenting Style (PIPS) is a measure that uses a 5-point Likert scale to assess parenting style after a trauma (Scheeringa et al., 2015). Two subscales were used in the current study: Avoidant (7 items) and Overprotective (3 items). Scores are summed, and greater scores indicate more avoidant/overprotective behaviors. The subscales of this measure have not been reported previously. In the current study, Cronbach's α's were acceptable, (avoidant subscale=.80, overprotective subscale=.74).

6.3.3 Statistical Analyses

Descriptive analyses were conducted using SPSS 24 for Windows. Hierarchical linear regressions were conducted to test the effect of procedural distress variables on child and parent psychological functioning at 6 months following injury. Potentially important control variables (demographic, procedural distress, parental acute psychological distress) were identified through correlational analyses using a conservative cutoff of $p<.1$.

Regression models were then forward built. Parenting stress at 6 months was entered as a control variable at Block 1 in in 6-month child functioning models. Similarly, child internalizing problems at 6 months was entered as a control variable at Block 1 in 6-month parent functioning models. Parenting stress and child internalizing problems were chosen for these analyses because inspection

of the Pearson's *r* bivariate correlational relationships indicated they had the strongest effects. Procedural distress variables that were univariately associated to the outcomes were entered at Block 2.

6.4 Results

At 6 months following the burn injury, 43 of 87 parents (49%) returned the questionnaire booklets. Considering the low rate of return, *t*-test analyses were conducted to compare the characteristics of questionnaire completers to non-completers. Injury severity (wound depth, %TBSA, length of healing time) and parental self-reported acute psychological distress (general anxiety/depression symptoms, procedural fear, PTSS, guilt) at first dressing change was not associated with study engagement at the 6 month follow up. Therefore, the data were considered missing at random.

6.4.1 Child functioning

One participant did not respond to any child-related items and was therefore not included in the analyses. Thus 42 participants completed child-related measures. A summary of the descriptive analyses and clinical significance regarding child psychosocial functioning is reported in Table 6.3.

Posttraumatic stress symptoms

Four parents omitted responses for 1–3 items on the YCPC. Considering the low rate of missingness, the item mean was entered for these cases. Of 42 respondents, two parents reported alternative traumas as traumatic for their child, and one parent reported that their child had not experienced any trauma. Therefore, 39 (93%) parents reported their child's burn injury/medical treatment as traumatic (of which 6 parents reported additional traumas). No child had a probable PTSD diagnosis, however, one child met cut-off for symptoms requiring clinical attention (13 symptoms) and 16 parents (41%) reported their child had mild symptoms. The mean number of reported symptoms was 1.17 (*SD*=2.27).

Emotional and behavioral problems

There were no clinically significant (*T*-score of 65–100) total behavioral problems or internalizing behavioral problems reported. One parent reported clinically significant externalizing behavior, and one parent reported borderline clinically significant externalizing behavior. The mean *T*-scores were 36.93 (*SD*=7.79) for internalizing symptoms, 40.98 (*SD*=10.99) for externalizing symptoms, and 38.24 (*SD*=8.59) for total behavioral problems.

Health-related quality of life

One child met criteria (≤83) for significantly impaired total health-related quality of life (score of 76). A small number of children had significant impairment in the physical (*n*=2), emotional (*n*=5), and social (*n*=3) domains.

Current pain

One participant did not respond to this item and was therefore not included in the analyses. The majority of parents (*n*=38) reported that their child was not currently experiencing any pain. Three parents reported mild current pain (score of 1–2 on an 11-point scale) for their child.

Table 6.3 Descriptive analyses and clinical significance for children

Measure	*N*	Mean (*SD*)	Study range	Clinical cases	Clinical cut-off	*n*	%
Burn-related PTSS	39	1.17 (2.27)	0–13	None	0	22	56
				Mild symptoms	1–11	16	41
				Clinical attention	12–25	1	3
				Probable diagnosis	26–68	0	0
Total behavioral problems	42	38.24 (8.59)	28–53	Normal range	28–59	42	100
				Borderline clinically significant	60–64	0	0
				Clinically significant	65–100	0	0
Internalizing symptoms	42	36.93 (7.79)	29–56	Normal range	28–59	42	100
				Borderline clinically significant	60–64	0	0
				Clinically significant	65–100	0	0
Externalizing symptoms	42	40.98 (10.99)	28–66	Normal range	28–59	39	93
				Borderline clinically significant	60–64	1	2
				Clinically significant	65–100	1	2
Total HRQL	42	96.72 (4.99)	76–100	Normal range	84–100	41	98
				Significant impairment	0–83	1	2
Physical health	42	98.88 (3.15)	84–100	Normal range	92–100	40	95
				Significant impairment	0–91	2	5
Emotional health	42	92.02 (10.94)	60–100	Normal range	76–100	37	88
				Significant impairment	0–75	5	12
Social health	42	97.50 (7.59)	60–100	Normal range	86–100	39	93

Measure	*N*	Mean (*SD*)	Study range	Clinical cases	Clinical cut-off	*n*	%
				Significant impairment	0–85	3	7
Current pain	41	0.10 (0.37)	0–2	None	0	38	93
				Mild	1–3	3	7
				Moderate	4–6	0	0
				Severe	7–10	0	0

Notes. PTSS=Posttraumatic Stress Symptoms; HRQL=Health-Related Quality of Life.

6.4.2 Parental functioning

A summary of the descriptive analyses and clinical significance regarding parent psychosocial functioning is reported in Table 6.4.

Posttraumatic stress symptoms

Five participants did not answer any items on this measure and therefore were not included in the analyses. Thus 38 participants completed this measure. Thirty-three parents (87%) reported a trauma history, of which 18 parents (47%) reported their child's burn injury as a traumatic event. Within parents who identified their child's burn injury as traumatic, no one reported clinically significant symptoms, however, 10 parents (56%) reported mild symptoms at 6 months post-burn injury. The mean number of symptoms for parents who reported the burn injury as traumatic were 1.61 (*SD*=2.00).

Parenting stress

A minority of missing data was found: Four parents did not respond to one item, and one parent did not respond to two items. Little's MCAR test revealed this data was missing completely at random. Therefore, the item median was imputed, and analyses were conducted on 43 parents. The majority (*n*=41) of parents reported parenting stress in the normal range. Two parents reported borderline clinically significant scores.

Trauma-affected parenting style

One parent did not answer any items on this measure and therefore were not included in the analysis. Thus 42 participants completed this measure. Parents reported a mean score of 6.90 (*SD*=4.81) for avoidant parenting behavior, and a mean score of 2.43 (*SD*=2.60) for overprotective parenting behavior.

Table 6.4 Descriptive analyses and clinical significance for parents

Measure	*N*	Mean (*SD*)	Study range	Clinical cases	Clinical cut-off	*n*	%
All PTSS	38	2.82 (7.83)	0–47	*None*	0	21	55
				Mild	1–10	15	39
				Moderate to severe	11–51	2	6
				Probable PTSD diagnosis		1	3
Burn-related PTSS	18	1.61 (2.00)	0–7	*None*	0	8	44
				Mild	1–10	10	56
				Moderate to severe	11–51	0	0
				Probable PTSD diagnosis		0	0
Total parenting stress	43	37.12 (27.89)	16–96	*Normal*	16–84	41	95
				High	85–90	1	2
				Clinically significant	91–99	1	2
Post-trauma parenting style							
Avoidant	42	6.90 (4.81)	0–23		0–28		
Overprotective	42	2.43 (2.60)	0–10		0–12		

Notes. SD=Standard Deviation; PTSS=Posttraumatic Stress Symptoms; PTSD=Posttraumatic Stress Disorder.

6.4.3 Parent and child symptoms at 6 months

The correlations of psychological impairment in children and their parents at 6 months are presented in Table 6.5. Parental PTSS was positively related to child total (r=.33, p=.050) and internalizing (r=.54, p=.003) behavioral problems, and negatively correlated to child emotional (r=-.46, p=.004) and total (r=.65, p<.001) HRQL. Parenting stress was similarly positively related to child total (r=.57, p<.001), internalizing (r=.36, p=.030), and externalizing (r=.46, p=.001) behavioral problems, and negatively correlated to child emotional (r=-.33, p=.024) and total (r=-.37, p=.017) HRQL. Avoidant parenting style was positively correlated to child total (r=.58, p<.001), internalizing (r=.55, p<.001), and externalizing (r=.44, p=.001) behavioral problems, and negatively correlated to emotional (r=-.46, p=.002) and total (r=-.52, p<.001) HRQL. Overprotective parenting was positively correlated to child internalizing behavioral problems (r=.49, p=.001).

Table 6.5 Correlation matrix of relationships between child and parent psychological problems at 6 months after the burn injury.

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
Child										
1. PTSS (*N*=42)	-	-.10	.01	-.13	-.04	-.09	.11	-.10	-.09	.11
2. Total behavior problems (*N*=42)		-	.64***	.93***	-.52***	-.51**	.33*	.57***	.58***	.21
3. Internalizing behavior (*N*=42)			-	.47**	-.53***	-.44**	.54**	.36*	.55***	.49**
4. Externalizing behavior (*N*=42)				-	-.42**	-.43**	.21	.46**	.44**	.09
5. Total HRQL (*N*=42)					-	.91***	-.65***	-.37*	-.52***	-.07
6. Emotional HRQL (*N*=42)						-	-.46**	-.33*	-.46**	-.02
Parent										
7. PTSS (*N*=37)							-	.43**	.66***	.35*
8. Parenting Stress (*N*=42)								-	.63***	.23
9. Avoidant parenting (*N*=41)									-	.52***
10. Overprotective parenting (*N*=41)										-

PTSS=Posttraumatic Stress Symptoms; HRQL=Health-Related Quality of Life. ***$p<.001$, **$p<.01$, *$p<.05$.

6.4.4 Procedural distress predicting child functioning at 6 months post-injury

Child functioning variables were tested for non-normality. Based on the extremely low rates of impaired functioning on current pain (*n*=3 of 41), social HRQL (*n*=3 of 42), and physical HRQL (*n*=2 of 42), it was not surprising that these variables displayed severe skewness and kurtosis and, therefore, were excluded from subsequent analyses. Externalizing behavior, internalizing behavior, total HRQL, emotional HRQL, and PTSS were within acceptable ranges.

No injury, procedural, or demographic variables were associated to child functioning. Pearson's *r* correlations between procedural distress during the first dressing change and 6-month child psychosocial problems were conducted. Table 6.6 reports the correlation matrix for procedural distress-related variables and child psychological outcomes.

Table 6.6 Correlations investigating procedural distress and 6-month child psychological outcomes

		PTSS (*N*=42)	Total behavior problems (*N*=42)	Internalizing behavior (*N*=42)	Externalizing behavior (*N*=42)	Total HRQL (*N*=42)	Emotional HRQL (*N*=42)
Child	*Parent-report*						
	Pain (pre)	.28^	-.20	-.08	-.21	.03	.08
	Pain (peak)	-.04	-.12	-.07	-.15	.15	.11
	Pain (post)	.01	.02	.12	.01	.11	.11
	Fear (pre)	.04	-.11	.05	-.13	-.04	-.01
	Fear (peak)	.10	-.15	.02	-.23	.08	-.00
	Fear (post)	-.08	-.06	-.01	-.04	.00	-.13
	Nurse-report						
	Pain-related distress (pre)	-.08	-.08	.02	-.10	.12	.08
	Pain-related distress (peak)	-.12	-.24	-.04	-.33*	.26^	.15
	Pain-related distress (post)	.13	.04	-.04	.07	.12	.11
	Observer-report (B-CAMPIS)						
	Coping	-.08	-.01	-.07	.09	-.01	.03
	Distress	-.07	.01	.10	-.03	.16	.06
	Observer-report (CAMPIS-SF)						
	Coping	.18	-.04	-.02	.02	-.23	-.14
	Distress	-.24	-.11	-.10	-.18	.26	.17
Parent	*Observer-report (B-CAMPIS)*						

	PTSS (*N*=42)	Total behavior problems (*N*=42)	Internalizing behavior (*N*=42)	Externalizing behavior (*N*=42)	Total HRQL (*N*=42)	Emotional HRQL (*N*=42)
Coping-promoting	-.11	.04	-.06	.05	.13	.13
Distress-promoting	-.09	.04	.08	.04	.17	.13
Observer-report (CAMPIS-SF)						
Coping-promoting	-.12	.13	.10	.13	.06	.09
Distress-promoting	-.17	-.02	-.02	-.09	.16	.08
Self-report						
General anxiety/depression	-.04	.32*	.37*	.26	-.61***	-.42**
Guilt	.15	-.04	.08	-.07	-.12	-.11
PTSS	.17	.07	.23	.03	-.04	-.02
Fear (pre)	.04	.08	-.05	.05	.05	.09

PTSS=Posttraumatic Stress Symptoms; HRQL=Health-Related Quality of Life; B-CAMPIS=Burns-Child-Adult Medical Procedure Interaction Scale; CAMPIS-SF= Child-Adult Medical Procedure Interaction Scale-Short Form. $^{***}p<.001$, $^{**}p<.01$,$^{*}p<.05$, $^{\wedge}p<.1$.

Psychological functioning

Inspection of the correlation matrix revealed there were no significant relationships with procedural distress variables and child psychological outcomes at 6 months. However, parental acute symptoms of anxiety/depression were significantly related to internalizing problems and lower emotional HRQL at 6 months.

Internalizing behavior

A hierarchical multiple linear regression was forward built to assess the effect of parental acute anxiety/depression symptoms on internalizing behavior at 6 months, after controlling for parenting stress at 6 months. See
Table 6.7 for the final models. Parenting stress at 6 months was entered as a control variable at Block 1, and accounted for 11% of the variance. Parental acute anxiety/depression symptoms was entered at Block 2 and accounted for an additional 9% of the variance. Parental acute anxiety/depression symptoms tended to be associated with their child's internalizing problems at 6 months, after controlling for parenting stress at 6 months.

Emotional HRQL

A hierarchical multiple linear regression was forward built to assess the effect of parental acute anxiety/depression symptoms on emotional HRQL at 6 months, after controlling for parenting stress at 6 months. Parenting stress at 6 months was entered as a control variable at Block 1, and accounted for 9% of the variance. General anxiety/depression symptoms were entered at Block 2 and accounted for an additional 13% of the variance. Parental acute anxiety/depression symptoms significantly predicted a lower emotional HRQL for their child at 6 months, after controlling for parenting stress at 6 months.

Table 6.7 Two hierarchical linear regression analyses predicting child psychological outcomes at 6 months after the burn injury

	Model 1 (*N*=42)			Model 2 (*N*=39)		
	ΔF	ΔR^2	β	ΔF	ΔR^2	β
Internalizing problems at 6 months						
B1. Parenting stress at 6 months	5.05*	.11	.34*	4.38*	.11	.25
B2. Acute general anxiety/depression				3.82^	.09	.30^
Emotional HRQL at 6 months						
B1. Parenting stress at 6 months	5.50*	.10	-.35*	3.79^	.09	-.21
B2. Acute general anxiety/depression				5.89*	.13	-.37*

HRQL=Health-Related Quality of Life. $^{*}p<.05$, $^{\wedge}p<.1$.

6.4.5 Procedural distress predicting parental functioning at 6 months post-injury

Parent psychological outcomes were tested for non-normality. Based on the extremely low rates of impaired functioning, the measure of parental PTSS was evaluated and excluded from analyses due to severe skew and kurtosis. Parenting stress, avoidant parenting style, and overprotective parenting style were within acceptable ranges. Procedural distress during the first dressing change was tested in relation to parent psychosocial impairment (analyzed as continuous variables). Table 6.8 reports the correlation matrix for procedural distress-related variables and parental psychosocial outcomes.

Table 6.8 Correlations investigating procedural distress and parent psychosocial outcomes

		Parenting Stress (*N*=43)	Avoidant parenting (*N*=42)	Overprotective parenting (*N*=42)
Child	*Parent-report*			
	Pain (pre)	-.14	-.13	.06
	Pain (peak)	-.05	.18	.39*
	Pain (post)	-.10	.11	.10
	Fear (pre)	-.04	-.12	-.15
	Fear (peak)	.06	.00	.12
	Fear (post)	-.03	-.02	-.13
	Nurse-report			
	Pain-related distress (pre)	.04	-.08	-.03
	Pain-related distress (peak)	-.08	-.01	.13
	Pain-related distress (post)	.01	.25	.32*
	Observer-report (B-CAMPIS)			
	Coping	-.09	-.15	-.20
	Distress	.04	.04	.13
	Observer-report (CAMPIS-SF)			
	Coping	.07	-.01	-.14
	Distress	-.15	.03	.19
Parent	*Observer-report (B-CAMPIS)*			
	Coping-promoting	.02	-.10	-.24

	Parenting Stress (*N*=43)	Avoidant parenting (*N*=42)	Overprotective parenting (*N*=42)
Distress-promoting	-.13	.06	.05
Observer-report (CAMPIS-SF)			
Coping-promoting	.23	.01	-.09
Distress-promoting	.00	-.02	-.04
Self-report			
General anxiety/depression	.30^	.55***	.31^
Guilt	.11	.12	.37*
PTSS	.17	.27^	.44**
Fear (pre)	.06	.03	.17

B-CAMPIS=Burns-Child-Adult Medical Procedure Interaction Scale; CAMPIS-SF= Child-Adult Medical Procedure Interaction Scale-Short Form.

***$p<.001$, **$p<.01$,*$p<.05$, ^$p<.1$

Parenting stress

No injury, procedural, or demographic variables were associated to parenting stress. Inspection of the correlation matrix revealed there were no significant relationships with procedural distress variables and parenting stress at 6 months.

Trauma-affected parenting style

No injury, procedural, or demographic variables were associated to trauma-affected parenting style. Inspection of the correlation matrix revealed there were no significant relationships with procedural distress variables and avoidant parenting at 6 months. However, there was a significant relationship between child procedural pain and overprotective parenting style (r=.39, p=.011). A hierarchical multiple linear regression was forward built to assess the effects of predictor variables on an overprotective parenting style at 6 months. See Table 6.9 for the final model. Child internalizing behavior at 6 months was entered as a control variable at Block 1 and accounted for 23% of the variance. Parent-reported child procedural pain was entered at Block 2, and accounted for an additional 16% of the variance. Greater parent-reported procedural pain at the first dressing change predicted an overprotective parenting style at 6 months, after controlling for parent-reported child internalizing behavior at 6 months.

Table 6.9 Hierarchical linear regression analysis predicting an overprotective parenting style at 6 months after the burn injury

	Model 1 (N=41)			Model 2 (N=40)		
	ΔF	ΔR^2	β	ΔF	ΔR^2	β
B1. Child internalizing behavior	11.94**	.23	.48**	11.22**	.23	.50***
B2. Parent-reported procedural pain				9.72	.16	.41**

***p<.001, **p<.01.

6.5 Discussion

Overall, parents reported low levels of child and parent psychological distress at 6 months following pediatric burn injury. These results contrast with previous studies in this population: At 6 months 5% of parents had a probable PTSD diagnosis (De Young et al., 2014), and 10% of children had PTSD (De Young et al., 2012). However, the lower prevalence found in this study may be explained by a number of reasons. Firstly, psychological distress was not assessed with a diagnostic tool, which is the gold-standard for identifying PTSD (American Psychiatric Association, 2013).

Secondly, due to the age of the child, their distress needed to be assessed by parent-report. Research has shown that parents typically under-report internalizing symptoms in children and this is particularly the case for young children (Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2008; Scheeringa, Wright, Hunt, & Zeanah, 2006). Future research should utilize validated diagnostic interviews to assist with the accurate identification of distress in young children. Another possible explanation is the low injury severity in the current study. While injury severity is not a good predictor of PTSS, some studies have reported significant associations (i.e., Haag & Landolt, 2017), which may have influenced the low rates of PTSS. Furthermore the small sample size might have made it difficult to detect PTSD, which is already understood to be a small percentage of the population. Finally, it is possible that with the advances that have been made in pediatric burn wound care, the children in this study may have received better pain management practices and thus experienced less potentially traumatic procedural events which may have contributed to the lower rates of long-term distress found in this study compared to other samples (De Young et al., 2012; Graf et al., 2011; Landolt et al., 2009). Notably, despite these advances, residual distress was still present for a small number of families at 6 months after the burn injury.

Contrary to hypotheses, procedural distress did not predict long-term child psychological impairment. However, the parent's acute symptoms of general anxiety and depression predicted the child's emotional HRQL and internalizing problems at 6 months. It is possible that a child's long-term emotional adjustment following injury is affected by how the parent also responds to the injury. Alternatively, the association could have been driven by genetic influence, or pre-existing symptoms of general anxiety and depression (i.e., not relating to the burn injury). Regardless of the onset, young children of parents with anxiety/depression symptoms appear at risk of poorer psychological recovery following a burn injury, and this suggests that children and parents can benefit from additional psychological support following a burn injury.

Procedural distress did not influence parental PTSS or parenting stress at 6 months. However, there was an effect of the child's procedural pain on 6-month post-trauma parenting style. Specifically, parents who reported higher procedural pain for their child at the first dressing change reported more overprotective parenting behavior 6 months later. In light of the correlations reported between parental acute psychological distress and trauma-affected parenting style at 6 months, and between trauma-affected parenting style at 6 months and child psychological impairment at 6 months, a mediation model is possible. However, the current sample size did not have sufficient power to conduct a mediation analysis. These findings are in line with the wider pediatric chronic pain literature, which has reported longitudinal effects of parental distress and behavior on child functioning (Chow, Otis, & Simons, 2016; Law et al., 2017; Palermo & Eccleston, 2009). It must be

considered, however, that the variables utilized in this regression are solely parent-reported, which may have inflated the finding. Future research with larger sample sizes and multiple informants is required to investigate changes in parenting behavior following a burn injury, and how this relates to psychological recovery. Understanding parenting changes is crucial for the development of tailored approaches for supporting parents following a child's injury.

Some limitations for the current analyses must be noted. It is important to note the small sample size and low questionnaire return rate (49%). It is possible non-respondents had poorer psychological outcomes, considering part of PTSS includes avoidance behavior and completing the questionnaire would have reminded them of the injury. Further, understanding the trajectories of PTSD, it is possible that responders and non-responders have different recovery trajectories (e.g., resilient vs. delayed onset). It was a limitation that parenting style was assessed using self-report. Future research should utilize observational measures of parenting behavior. Another limitation is that other general stressors were not reported. It is possible that the reported impaired functioning for child and parent was due to factors beyond the burn injury yet not stated in the trauma screen, such as bullying or marital conflict. It must be noted that in the absence of alternatives, two measures (PedsQL, CBCL) were applied to a minority of children whose ages beyond what they have been validated for. Another concern is that even with a priori hypotheses, a large number of analyses were conducted without statistical correction. Finally, it is a limitation that the child was not screened for acute PTSS. Acute child traumatic stress is predictive of long-term child psychological outcomes (De Young et al., 2014), and future research should take this into account when investigating child and parent psychological outcomes following a burn injury.

The findings of this study agree with previous calls for distress screening in the family following a child's burn injury (Fukunishi, 1998; Hall et al., 2006). Future research must focus on translating lasting psychological interventions for families. In the months after a minor burn has healed, these results indicate that a small proportion of young children and parents can continue to experience psychosocial problems. Parental acute psychological distress has long-term consequences for their child's own adjustment. Early parent-level psychological and behavioral interventions are likely to be important for mitigating the psychological impact of pediatric burn injury on families.

Chapter 7. Discussion

7.1 Preamble

This chapter is the final chapter of the thesis. This chapter aims to 1) discuss the overall findings in relation to the research aims and questions; 2) discuss overarching limitations of the thesis; 3) recommend future directions of research, and; 4) describe the clinical implications of this thesis.

7.2 Research aims and questions

This thesis investigated how parents influence their young child's procedural distress and recovery following burn injury. Specifically, the thesis aimed to 1) review the literature and propose a theoretical model to help understand the relationship between parent and child distress during medical procedures which could then be narrowed to focus on the burn injury context; 2) develop and validate an observational measure for young child-parent burn wound care interactions; 3) test a theoretical model of the relationship between parent and child distress during the first burn dressing change; 4) present and test a theoretical model to help understand the parent's influence on child wound healing, and; 5) report the long-term psychosocial outcomes of young children and their parents and the effects of initial child and parent distress on these outcomes.

7.2.1 Review the literature and propose a theoretical model

A comprehensive review of the literature found that parental psychological distress was likely to be important for child coping during medical procedures, as well as their subsequent physical and psychological recovery. Several gaps in the literature were identified, including the availability of validated observational measures for young children (<7-years-old) undergoing burn wound care procedures, and studies that tested the effect of parental traumatic distress on pediatric procedural distress and investigated how initial distress influences physical and psychosocial recovery. A review of theories found the mechanism by which parental distress influences the child is likely through parenting behavior. Based on theories from the anxiety and posttraumatic stress literature (Fisak Jr & Grills-Taquechel, 2007; Scheeringa & Zeanah, 2001), a model was presented in which parents with psychological distress were less able to provide emotion co-regulation and display more distress-promoting or reassuring behaviors to their child during pediatric medical procedures.

7.2.2 Develop and validate an observational measure

A review of the literature found there was no appropriate parent-child observational measure for use with young children and parents during burn wound care. In order to address this gap, the B-CAMPIS was developed. The development was based on existing measures (Blount et al., 1997; Caldwell-Andrews et al., 2005; Cohen et al., 2005) and expanded to include nonverbal behaviors (i.e., playing), and burn wound care-specific behaviors (i.e., verbal disgust at wound). The data from the measure was collected *in vivo* and via audio recording rather than video recording as an acknowledgement of the sensitivity of the situation for parents and staff. The measure demonstrated acceptable reliability, as well as convergent and incremental validity.

7.2.3 Test the relational model of parent and child distress

The theoretical model of the relationship between parent and child distress that was derived from the literature review was tested during the child's first dressing change. Testing this model was a unique and crucial contribution of the thesis, as the field has not previously included empirical investigation of models of child procedural distress based on parental injury-related psychological distress. Results of the study supported a model of parental acute psychological distress influencing child procedural behavior via parenting behavior. However, parental psychological distress symptoms differentially statistically influenced the child's behavior. Parental anxiety/depression symptoms were associated with less frequent child coping behavior, mediated through less frequent coping-promoting behavior; conversely, parental PTSS and feelings of guilt were associated with more frequent child distress behavior, mediated through more frequent distress-promoting behavior. A modified version of the model was proposed. Although this was the first study to test the model, these findings were unexpected and suggest that parents experiencing PTSS behave differently towards their child during burns wound care than parents experiencing anxiety/depression symptoms. Further research is required to confirm these results.

7.2.4 Present and test a model of parent-wound healing

Although psychological stress has repeatedly been linked to delayed wound healing (Walburn et al., 2009), parental stress in the context of a child's burn wound healing has not been previously investigated. After controlling for injury severity and parent-reported procedural pain, parental PTSS significantly influenced the child's rate of wound healing. The results are novel and a critical finding of the thesis, and potential mechanisms of stress and inflammatory processes (i.e., parenting behavior that contributes to increased child stress and externalizing behaviors) are discussed. Replication of these results and exploration of the mechanism of influence are required. In addition, parent-reported child procedural pain predicted time to healing, similar to previous research of self-reporting older children (N. J. Brown, Kimble, Gramotnev, et al., 2014; K. Miller et al., 2011). The separate influences of parental PTSS and parent-reported procedural pain suggest two different pathways, and that the influence of parental distress on wound healing is not explained by the parent's interpretation of child pain.

7.2.5 Report the long-term psychosocial outcomes

The majority of responding parents reported normal ranges of child and parent psychosocial functioning 6 months following a burn injury. A small number of parents reported ongoing psychosocial problems for both their child and themselves. Clinical significance for child impaired functioning was reached for burn-related PTSS (3%), externalizing behavior (4%), HRQL

(total=2%, physical=5%, emotional=12%, social=7%), and current pain (7%). For parents, clinical significance was reached for burn-related PTSS (56%) and parenting stress (4%). This finding is consistent with other longitudinal research (De Young et al., 2014; De Young et al., 2012).

Procedural distress did not influence child psychological functioning at 6 months. However, parental acute general anxiety/depression symptoms were associated with lower child emotional HRQL and more internalizing behavior at 6 months. This finding is consistent with the broader literature that has found parental mental health influenced child adjustment to an illness diagnosis (Ferro, Avison, Campbell, & Speechley, 2011).

Parent-reported child procedural pain predicted more overprotective parenting behavior at 6 months. Furthermore, correlational analyses demonstrated relationships between 1) parental acute psychological distress (PTSS, guilt, anxiety/depression) and an overprotective parenting style at 6 months; and 2) an overprotective parenting style at 6 months and poorer child psychological functioning at 6 months. The results indicate that a parent's acute psychological symptomology following burn injury may affect their parenting behavior over the long-term, which is likely to impact the child.

7.3 Limitations

Several limitations have been previously discussed with regards to the focus of each chapter. Additional limitations of the project as a whole are discussed here.

Overall, the role of child traumatic stress was not assessed at the first dressing change. Although research indicates parental PTSS perpetuates child PTSS over time (De Young et al., 2014; Landolt et al., 2012), children can also have independent traumatic stress reactions (De Young et al., 2014), and this was not accounted for in relation to child procedural behavior, physical healing, or 6-month psychosocial functioning. Future research should investigate the child's own traumatic stress in relation to their procedural distress, wound healing, and long-term psychological functioning.

The role of other family members and healthcare professionals (nurses, doctors, students, occupational therapists, physiotherapists, social worker, researchers, etc.) was not assessed. This investigation focused on a single parent's interaction with the child, however, the other people present were likely to have had effects on the parent and child's behaviors. When both parents were present the researcher only asked one parent to participate, which the parents decided between themselves. It is possible that the elected parent was more engaged with the research as they were experiencing less distress. Alternatively, the elected parent may have preferred to engage with the questionnaire rather than engage with the medical procedure. Furthermore, when two parents were present, it was observed that one parent tended to provide the majority of the support to the child,

and this may or may not have been the parent recruited for the study. If the behavior of both parents had been accounted for in the study, the parent's influence on child behavior might have been stronger. Given that the majority of participating parents were mothers, the relative effects of fathers' behaviors are not clear. Healthcare professionals are also interacting with parents and children, and research suggests healthcare professionals and parents mirror each other in terms of behavior towards the child (Cohen et al., 2005). However, it is noteworthy that healthcare professional behavior is not as influential as parent behavior for child procedural distress (Racine, Pillai Riddell, Flora, et al., 2016). Future research could consider a triadic model of behavior to reflect the procedural experience.

Limitations with the design of the research must also be noted. The mediation analyses were cross-sectional in nature, such that parent and child behavior was not analyzed sequentially. Sequential analyses of parent and child behavior have been previously investigated, and a bidirectional relationship was found: Parent distress-promoting behavior preceded child distress behavior, *and* vice versa (Blount et al., 1989). Further, there was no experimental manipulation with regards to parental acute psychological distress or behavior (which would not have been ethical), and therefore causation cannot be inferred.

This thesis focused on parent-report measures for the majority of child-related variables. As raised previously, parent-report is often correlated with child self-report, but differences have been found (Chambers et al., 1998). Specifically, some of the children in this sample were able to self-report pain intensity (there were 17 children aged 5–6-years-old, 20% of the sample, see Table 3.3), however, were not given the opportunity to do so. Pain is inherently a subjective experience and self-reported data should be included in study designs whenever possible.

Consideration must be given to the setting in which the research took place. Burn wound care is not standardized across Australia, or internationally (i.e., medical treatment such as the type of analgesia, use of debridement, type of dressing, grafting technique, or psychological support such as the involvement of a psychologist) (Beerthuizen et al., 2017; ISBI Practice Guidelines Committee et al., 2016). These differences can influence procedural pain as well as availability of sufficient psychological support. In terms of psychological support, the Pegg Leditschke Children's Burns Centre provides the Ditto™ device, and a social worker is available to assist with families as alerted by the clinical team. In comparison, other pediatric burns centers employ Child Life therapists, psychiatrists, and psychologists to provide psychological and procedural distress support (Ohgi & Gu, 2013). Furthermore, some international pediatric burns centers do not allow parents to be present for wound care (Egberts, de Jong, et al., 2018), as concerns have been raised regarding the potential for distressed parents to increase child distress (Stoddard et al., 2002). Beyond

psychological support, type of dressing is not standardized across pediatric burns centers, which can also influence procedural pain as well as the frequency of painful dressing changes (Gee Kee, 2016). Recommendations borne from this research project should be considered in light of the setting characteristics.

This thesis assumes that previously identified coping-promoting and distress-promoting behaviors are beneficial for families of all cultures. An association between parent ethnicity (favoring Anglo/European) and more coping-promoting behavior was found (reported in Chapter 4). There are multiple potential reasons for this association. The majority of the work identifying positive parenting behavior has been undertaken in North American Caucasian families. The B-CAMPIS itself should be considered a measure of Australian Caucasian parenting behavior. However, non-Anglo/European families tend to have different parenting/attachment styles (Keller et al., 2005; Keller et al., 2004; Russell et al., 2003), and this might lead to different behaviors during pediatric medical procedures (Kristjansdottir et al., 2018). Additionally, families from other cultural backgrounds may not be familiar with how the healthcare system operates, and/or experience stereotyping by healthcare professionals (National Research Council Panel on Race Ethnicity Health in Later Life, 2004), leading to reluctance to proactively engage with the child during the medical procedure. Finally, culture influences how pain is expressed (Strong et al., 2015), and lack of understanding by healthcare professionals can lead to suboptimal care. It is critical to understand appropriate emotion co-regulation strategies for families of diverse cultural backgrounds to ensure future behavioral interventions are accepted and effective for reducing child procedural distress. Therefore, caution is warranted regarding applying existing observational measures and interventions to increase positive parenting behavior in families of other cultures. Understanding these limitations assist with providing future directions for this research topic.

7.4 Research implications

The highlighted findings and limitations provide directions for future research. Specifically, future work should develop and test a resource for supporting parents of young children undergoing burn wound care. Price et al. (2016) suggest that one way to intervene to reduce PTSS is to change the subjective experience. Based on the findings of this thesis, a resource providing procedural preparation, psychological coping strategies, and encouraging specific procedural behavior, could be developed to improve the child's and parent's experience of burn wound care. The resource ideally would be engaging (i.e., a video mode of delivery) and short (i.e., optimally 6 minutes or less in time, see Brame, 2016) to be feasible for use in a busy clinical environment. The resource could be targeted, for example for parents screened for acute anxiety/depression compared to

parents screened for acute PTSS. Alternatively, a universal approach could also reduce pediatric procedural distress, as all parents may benefit from procedural information and behavioral recommendations. The behavioral strategies would likely include coping-promoting behavior such as distraction and coaching the child in deep breathing. Parents could be taught to use these behaviors using modelling, information transfer, and reinforcement strategies, which has been identified as important for parent-child transmission of anxiety (Fisak Jr & Grills-Taquechel, 2007). Finally, as indicated by best practice guidelines it is important to involve parents when developing such a resource (Shen et al., 2017), as well as test acceptability (of parents) and feasibility (of use in the clinical environment), prior to testing the efficacy of the resource (Leon, Davis, & Kraemer, 2011). Although not discussed in this thesis, the results have led to the development of such an intervention.

An alternative approach may be to intervene at the healthcare professional level. As discussed, healthcare professionals are interacting with families throughout the procedure. From the research presented in this thesis, it is unclear the role that the healthcare professionals played as their behavior was not analyzed. Healthcare professionals could potentially be trained to provide additional support for parents in conjunction with the video resource, or as an alternative model of intervention. Without training, healthcare professionals may act as a barrier to parents using the video-endorsed coping-promoting behaviors. Training might help healthcare professionals proactively support parents to use coping-promoting behaviors throughout the procedure. Training can provide healthcare professionals with a trauma-informed framework for responding to these disclosures in a sensitive and beneficial way. Suggestions have been offered about how healthcare professionals can use trauma-informed care in pediatric healthcare settings (Marsac et al., 2016).

7.5 Clinical implications

Beyond research driven intervention development, there are multiple clinical implications of the findings of this thesis. Of note, these implications are in the context of a relatively minor burn injury; there may be different implications for families of children with larger (i.e.>20%TBSA) burns. Although many pediatric burns centers now allow parents to be present for burn wound care, parental presence has been much debated, due to the concern around parental psychological distress (Stoddard et al., 2002). Recent work has identified that the majority of parents want to be present (Egberts, de Jong, et al., 2018), and findings of this thesis have two key implications for clinicians. Firstly, independent of the actual severity of the wound, parents can still experience acute psychological distress after a child's burn injury. An awareness of parental psychological distress, and understanding how to provide parents with psychological and behavioral support during

dressing changes can be valuable for improving procedural experiences. Specifically, acknowledging the parent's feelings of guilt or distress while encouraging the parent to focus on helpful behaviors such as distraction, may provide the parent with a purpose during the procedure that increases parent and child coping.

The second clinical implication is identifying the importance of intervening with families at the first dressing change (or earlier) for improving the child's wound healing and psychosocial recovery. To facilitate wound healing, burns clinicians must recognize the importance of reducing procedural pain using a range of evidence-based pharmacologic and non-pharmacologic interventions. Furthermore, burns clinicians should also take into consideration that wound healing might be delayed for children of parents with PTSS, and tailor treatment to diminish the influence of parental PTSS. To improve psychological recovery, psychologists could investigate how to intervene with parents experiencing acute psychological distress. Acute distress reactions are considered normal and typically decrease with time (De Young et al., 2014), although research has shown improved parental psychological recovery following acute (<3 days post-injury) intervention (Kenardy, Thompson, Brocque, & Olsson, 2008). Considering parental PTSS appears to contribute to child PTSS development (De Young et al., 2014), parents and children are likely to both benefit from parent-focused acute intervention. Further work is required to identify how best to intervene, although it might involve key suggestions for increasing coping strategies and monitoring parenting behavioral changes during this acute period.

7.6 Conclusion

This thesis identified the influence of parental acute psychological distress on pediatric procedural distress, wound healing, and six-month psychosocial functioning following a burn injury. These findings have implications for the clinical treatment of children undergoing burn dressing changes, and the development of psycho-behavioral interventions for supporting parents. The next step is to create and test interventions for these parents. With adequate support, parents can be important resources for managing young child procedural distress during burn wound care.

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Appendices

Appendix A. Ethics approvals

CHILDREN'S HEALTH QUEENSLAND
HOSPITAL AND HEALTH SERVICE
HUMAN RESEARCH ETHICS COMMITTEE

Professor John Pearn (Chair) 3365 5323
Mrs Amanda Smith (Co-ordinator) 3636 9167

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Level 3, RCH Foundation Building
Royal Children's Hospital
Herston QLD 4029 Australia
Telephone (07) 3636 9167

21st April 2015

Ms Erin Brown
CONROD
Level 7, UQ Oral Health Centre
Royal Brisbane and Women's Hospital
Herston QLD 4029

Dear Ms Brown,

HREC Reference number: HREC/15/QRCH/27
Project title: An observational study on how parental distress affects child outcomes in the children's burns unit

Many thanks for your letter of the 1st April with responses to queries raised by the Committee in relation to the above project. Further to our letter of the 1st April granting approval, please note the following;

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I am pleased to advise the proposal meets the requirements of the National Statement on Ethical Conduct in Human Research and the Committee is happy to give approval.

This project has Ethics approval for the following sites:

- Lady Cilento Children's Hospital, Brisbane

Note: If additional sites are engaged prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the HREC. Notification of withdrawn sites should also be provided to the HREC in a timely fashion.

The documents reviewed and approved include:

Document	*Version*	*Date*
Covering Letter	1	26 February 2015
Protocol	1	02 March 2015
Questionnaire: Pre procedure questionnaire	1	02 March 2015
Questionnaire: Post procedure Questionnaire	1	02 March 2015
Questionnaire: 3 month follow up questionnaire	1	02 March 2015
Application		
Covering Letter		01 April 2015

Response to Request for Further Information		01 April 2015
Patient Information Sheet/Consent Form	2	25 March 2015

Please note the following conditions of approval:

1. We require an annual progress report (or sooner if the project is completed) concerning the study. This must include progress to date or outcome in the case of completed research. Ethics approval is for 3 years from date of this letter. (In accordance with National Statement 5.5.3)

2. In accordance with the National Statement (3.3.12), before beginning the clinical phase of the research, researchers should register clinical trials in a publicly accessible domain.

3. Please note if identifiable or potentially re-identifiable data for this research project is to be accessed without je written consent of the person to whom the data relates an application for disclosure of this data must be made under the *Public Health Act.* Further information regarding the *Public Health Act* is available via this link: **http://www.health.qld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp**

4. If the project does not proceed, the Committee must be informed as soon as possible. (In accordance with National Statement 5.5.6)

5. The Committee must be informed of any potential or realised problem with bioethical implications, if such occurs during the conduct of the research project.

6. Any serious adverse event (SAE) that arises in the context of this research, or involving a researcher conducting this research, must be reported to the Ethics Committee within 72 hours and reported to the sponsor (if applicable) within the stipulated time frame.

   Serious Adverse Event Reports that are generated off-site may be (a) Serious Unexpected Adverse Reactions or (b) Serious Events which the Research Team believes cannot be related to the research intervention. The Research team must report incidents of (a) during multi-centre trials. Such are required to be submitted to the Chair of HREC on receipt by the researcher. A summary of the SAE reports is to accompany the submission. Information required includes; patient details (age & sex), adverse event, outcome and the likelihood of the event being related to the study drug/device/procedure.

   With respect to all SAEs, the researcher must provide his or her opinion as to whether the SAE is directly related to the research intervention. A copy of the SAE Summary must be provided. (This can be obtained from the Ethics Officer)

7. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a revised online NEAF (accompanied by all relevant updated documentation and a cover letter from the principal investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study). Hard copies of the revised NEAF, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC and the RGO as per standard HREC/RGO SOP.

8. The Ethics Committee may conduct a randomly identified audit of a proportion of research projects approved by the Committee. That audit process will look at such issues as;
   a. Security of Documents
   b. Consent Form Register
   c. Serious Adverse Events Register
   d. Withdrawal of Participants – who and why
   e. The de-identification of data

9. Ethical approval to undertake this research project is given on the understanding that you have an intention to publish your findings in a refereed journal or similar peer-reviewed forum. If you do not have this intention, it is an absolute requirement that you notify the Ethics Committee formally. In this latter instance, approval for this research is not given at this time; and will require further negotiation. Your work must be in accordance with the following:

   - *National Statement on Ethical Conduct in Human Research:* **https://www.nhmrc.gov.au/guidelines/publications/e72**
   - *Queensland Health Management Research Policy:* **http://www.health.qld.gov.au/ohmr/html/regu/resrch_mge_policy.asp**
   - *Declaration of Helsinki:*

http://www.wma.net/en/30publications/10policies/b3/17c.pdf

- *Guidelines under Section 95 of the Privacy Act1995 and Guidelines approved under Section 95A of the Privacy Act 1995.*
  http://www.health.qld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp
- *Queensland Health Privacy Guidelines IS42 & IS42A:*
  http://www.health.qld.gov.au/privacy/IS42A.asp

10. Researchers should note, if not QLD Health employees, a Blue Card may be required for contact with children.

11. The Researcher must send the **'Notification of Commencement of Research Protocol'** as soon as research begins. Status of the project will remain as 'Not Started' until this form is received.

Should you have any queries about the HREC's consideration of your project please contact Amanda Smith (Co-ordinator) or Professor John Pearn (Chairperson). The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from: http://www.health.qld.gov.au/ohmr/html/regu/regu_home.asp

You are reminded that this letter constitutes ethical approval only. This project cannot proceed at any site until separate research governance authorisation has been obtained from the CEO or Delegate of the institution under whose auspices the research will be conducted at that site.

The HREC wishes you every success in your research.

Yours sincerely,

Professor John Pearn
Chair
Children's Health Queensland
Hospital and Health Service
Human Research Ethics Committee

Queensland Government

Queensland **Health**

CHILDREN'S HEALTH QUEENSLAND HOSPITAL AND HEALTH SERVICE

CHQ RESEARCH

Enquiries to: CHQ Research
Telephone: (07) 3636 4445
Facsimile: (07) 3636 4175

Our Ref: SSA/15/QRCH/63

06 May 2015

Ms Erin Brown
CONROD
Level 7 of UQ Oral Health Centre
Royal Brisbane and Womens Hospital
Herston QLD 4029

Dear Mrs Penny,

HREC reference number: HREC/15/QRCH/27
SSA reference number: SSA/15/QRCH/63
Project title: An observational study on how parental distress affects child outcomes in the children's burns unit

The above mentioned research project has successfully received Institutional approval following review in May 2015.

Please be advised of the allocated Human Research Ethics Committee (HREC) and SSA reference for your study and quote them when communicating with our office for study identification purposes.

Ethics approval for this project was granted on 21 April 2015 by CHQ HREC under streamlined ethical review. A list of approved documents is contained in your HREC approval letter.
In addition, the following site specific documents have been reviewed and authorised:

Document	*Version*	*Date*
CHQ LNR Site Specific Assessment Form		13 April 2015
Response to Further Information – SSA		21 April 2015
CHQ HREC Approval Letter *(noted)*		21 April 2015

Cont:

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

1. Proposed AMENDMENTS to the research protocol or conduct of the research which may affect the ethical acceptability of the project are to be submitted to the HREC for review. A copy of the HREC approval/rejection letter must be submitted to the Research Governance Office;
2. Proposed AMENDMENTS to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to the Research Governance Office;
3. Proposed AMENDMENTS to the research protocol or conduct of the research which may affect both the going ethical acceptability of the project and the site acceptability of the project are to be submitted firstly to the HREC for review and then to the Research Governance Office after a HREC decision is made.
4. Annual reports and final reports are to be submitted to your approving HREC as well as the Research Governance Office.
5. Please inform the Research Governance Office of any extension to the duration of the project approved by the HREC. Your site authorisation is in conjunction with the validity of your HREC approval.
6. The Research Governance Office may conduct a random audit of your study at any time.

May I take this opportunity to wish you every success with your research project and the contribution it will make to Children's Health Queensland and the broader research community.

Yours Sincerely

Sue McKee
General Manager Operations
Children's Health Queensland
Hospital and Health Service

7 / 5 / 15

THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	An Observational Study on How Parental Distress Affects Child Outcomes in the Children's Burns Unit
Chief Investigator:	Ms Erin Brown, Prof Justin Kenardy, Prof Roy Kimble, Dr Alexandra De Young
Supervisor:	Prof Justin Kenardy, Prof Roy Kimble, Dr Alexandra De Young
Co-Investigator(s):	None
School(s):	Psychology
Approval Number:	2015000623
Granting Agency/Degree:	None
Duration:	7th July 2017

Comments/Conditions:

Expedited review on the basis of approval from the Children's Health Queensland HHS HREC dated 21/04/2015

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Medical Research Ethics Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

Signature _____ Date 27/4/2015

Appendix B. B-CAMPIS nonverbal behavior coding sheet

DATE: ____/____/____ Participant ID: _____

AGE: 1 2 3-6 ***RATER:***_____

DRESSING REMOVAL start ___:___ stop ___:___ total secs_____

Child		**Parent**	
Playing		Point to distract	
Pointing to décor		Contact to reassure	
Flailing		Distract	
Requires restraint		Crying silently	
Self-soothing		Point to distract	
Gaze to injury			
Gaze to parent			
Ditto			
Watch TV			
Aggression			

INTERMEDIATE start ___:___ stop ___:___ total secs_____

Child		**Parent**	
Playing		Point to distract	
Pointing to décor		Contact to reassure	
Flailing		Distract	
Requires restraint		Crying silently	
Self-soothing		Unengaged-distress	
Gaze to injury			
Gaze to parent			
Ditto			
Watch TV			
Aggression			

WASH AND CLEAN **start ___:___** **stop ___:___** **total secs_____**

Child		**Parent**	
Playing		Point to distract	
Pointing to décor		Distract	
Flailing		Contact to reassure	
Requires restraint		Crying silently	
Self-soothing		Unengaged-distress	
Gaze to injury			
Gaze to parent			
Ditto			
Watch TV			
Aggression			

RECOVERY (2 min) **start ___:___** **stop ___:___** **total secs_____**

Child		**Parent**	
Playing		Point to distract	
Pointing to décor		Distract	
Flailing		Contact to reassure	
Requires restraint		Crying silently	
Self-soothing		Unengaged-distress	
Gaze to injury			
Gaze to parent			
Ditto			
Watch TV			
Aggression			