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Pediatric medical traumatic stress : the impact on children, parents and staff

Sarah McGarry
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Paediatric Medical Traumatic Stress: The Impact on Children, Parents and Staff

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This thesis is presented for the award of Doctor of Philosophy

This research was conducted in conjunction with Princess Margaret Hospital for Children

June 2013

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

- i. incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;
- ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or
- iii. contain any defamatory material.

This thesis contains published work and work prepared for publication, some of which has been co-authored. The bibliographical details of the work are presented for each paper. The work involved in designing the studies described in this thesis was performed primarily by Sarah McGarry (the candidate).

The thesis outline and experimental design was planned and developed by the candidate, in consultation from Dr Sonya Girdler, Assoc. Prof. Catherine Elliott, Assoc. Prof. Jane Valentine, Assoc. Prof. Ann McDonald, and Prof. Fiona Wood (the candidate's supervisors).

All participant recruitment and management was carried out by the candidate. In addition, the candidate was responsible for all data analysis. The candidate drafted the original thesis with Dr Sonya Girdler, Assoc. Prof. Catherine Elliott and Prof. Fiona Wood providing feedback on drafts until the examinable version was finalised.

Student signature:



Primary supervisor signature:



Abstract

Burns are one of the most painful and traumatising injuries an individual can sustain and constitute a serious global health threat to children. Despite the magnitude of this public health problem, little research has examined the psychological burden of these injuries. This study used a mixed-methods approach to investigate the effect of paediatric medical trauma on children who have sustained a burn, their parents and the healthcare professionals caring for these patients. The paediatric medical traumatic stress model provided a theoretical framework for this study.

Firstly, this study aimed to gain an understanding of the lived experience of children who sustain a burn. Using phenomenology as a methodology, the first paper in this thesis provided an in-depth understanding of children's perceptions, thoughts and feelings about the lived experience of sustaining a burn. The findings identified two phases of trauma that are central to the burn experience. The paper found that children experience ongoing trauma in addition to the initial trauma of sustaining the burn, resulting in a cumulative trauma experience. Six themes were identified in the data describing the child's experience: ongoing recurrent trauma; return to normal activities; behavioural changes; scarring-the permanent reminder; family functioning and adaptation. The methodology of this research provided a voice for the child's perspective of the burn experience and the findings can be used to inform clinical care at all stages of the burn journey.

The second paper, a cross-sectional study, aimed to investigate the impact of exposure to paediatric trauma on parents of children with a burn and to identify risk factors and relationships between psychological distress and resilience. The results indicated that parents experienced significantly more symptoms of post-traumatic stress disorder than a comparative population. Factors including having a daughter, witnessing the event, feeling helpless or having past traumatic experiences significantly influenced symptoms of psychological distress and resilience. Findings from this study highlight that health professionals should screen parents to identify those at greatest risk and

provide effective evidence-based interventions aimed at improving resilience and reducing stress, as part of standard, routine care.

The aim of the third paper was to gain an understanding of the lived experience of parents of a child with a burn injury. Using a phenomenological, qualitative methodology allowed aspects of the parents' experience not collected in standardised outcome measures to be identified, enabling triangulation with the quantitative results found in the second study. The findings demonstrated that the experience of parents reflected a journey that was represented by three phases: the event, the inpatient phase and the return to the community. Within the three phases, themes of external stressors, emotional and behavioural responses and coping strategies were identified. These findings can be used for the development of protocols to underpin a comprehensive information and social support management plan for families. This would complement the surgical and medical treatment plan, providing direction for comprehensive service delivery.

Children, parents and health professionals are interconnected in a professional relationship. The aim of the fourth paper was to investigate the effect of exposure to paediatric medical trauma on multidisciplinary teams and the relationships between psychological distress, resilience and coping skills. Health professionals experienced significantly more symptoms of psychological distress and less resilience than comparative groups. Non-productive coping was associated with adverse psychological outcomes and younger health professionals were more vulnerable to psychological distress than those aged 25 years and above. Findings from this study may assist in developing organisational systems to facilitate optimal mental health and coping strategies in health professionals, with the aim of the maintenance of a healthy workforce.

Overall findings from this research provide evidence for health professionals to optimise a holistic clinical service at all stages of the burn journey. These findings provide previously unknown knowledge about the impact of paediatric medical trauma on children, parents and health professionals within a paediatric hospital.

Acknowledgements

Many individuals have made this research possible and I would like to extend my appreciation and gratitude to the following people.

To my primary supervisors Sonya Girdler and Catherine Elliott, thank you for inspiring me to begin a PhD, for providing me with the opportunity and for supporting me throughout the journey. I have learnt so much from you both and I am truly grateful for your support.

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To the staff in the Department of Paediatric Rehabilitation and the Total Care Burns Unit at Princess Margaret Hospital, thank you for your support and assistance during data collection. I would like to especially thank Suzanne Rea and Tania McWilliams for their support.

I am grateful for having the opportunity to finish writing my thesis on the Telstra Burns Reconstructive and Rehabilitation Unit at Royal Perth Hospital. I would like to thank all the staff on the unit, as well as staff from the Fiona Wood Foundation. I appreciate all the support provided.

I would especially like to thank my family. To my parents Mary and Gerry, I cannot express how grateful I am for your support and constant encouragement. I could never have achieved this without you. To Claire and Rick, you have supported me immensely throughout this journey and I am so grateful; and to my Nana, thank you for your guidance.

Finally, to the children, parents and health professionals who participated in this research, thank you for your honesty and time. Without your commitment to participating in this research, none of this would be possible. As my supervisor and mentor Fiona Wood states, ‘The quality of the outcome must be worth the pain of survival’. I hope this research is one of many steps forward to achieving this, and I dedicate this thesis to all the children on the Burns Unit at Princess Margaret Hospital.

Publications and Abstracts

The following is a list of publications and abstracts to which I have contributed during the course of my candidature arising from this thesis.

Peer-Reviewed Publications

1. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott, C (2013). Paediatric medical trauma: the impact on parents of burn survivors. Burns; [http:// dx.doi.org/10.1016/j.burns.2013.01.009](http://dx.doi.org/10.1016/j.burns.2013.01.009)
2. **McGarry S**, Girdler S, McDonald A, Valentine J, Lee S, Blair E, Wood F, Elliott, C (2013). Paediatric health care professionals: relationships between psychological distress, resilience and coping skills. The Journal of Paediatrics and Child Health. (Article accepted for publication.)
3. **McGarry S**, Elliott C, McDonald A, Valentine J, Wood F, Girdler S (2013). Paediatric burns: from the voice of the child. Burns. (Article accepted for publication, manuscript number: JBUR-D-13-00134.)
4. **McGarry S**, Elliott C, McDonald A, Valentine J, Wood F, Girdler S (2013). *'This is not just a little accident': a qualitative understanding of paediatric burns from the perspective of parents.* Disability and Rehabilitation. (Article under review, manuscript number; TIDS-03-2013-015.)

Peer-Reviewed Conference Abstracts

1. **McGarry S**, Girdler S, McDonald A, Valentine J, Blair E, Lee S, Wood F, Elliott C (2011). Paediatric medical trauma: the impact on multidisciplinary teams. Proceedings of the Occupational Therapy Asia Pacific Congress, November 2011, Chiang Mai, Thailand.
2. **McGarry S**, Girdler S, McDonald A, Valentine J, Blair E, Lee S, Wood F, Elliott C (2011). Paediatric medical trauma: the impact on multidisciplinary

teams. Proceedings of the Child and Adolescent Health Research Symposium July 2011, Princess Margaret Hospital, Perth, Western Australia.

3. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott C (2012). Paediatric medical trauma: the impact on parents of burn survivors. Proceedings of the Telethon Institute of Child Health Research; Student Symposium, June 2012, Perth, Western Australia.
4. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott C (2012). Paediatric medical trauma: the impact on parents of burn survivors. Proceedings of the Child and Adolescent Health Research Symposium, July 2012, Princess Margaret Hospital, Perth, Western Australia.
5. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott C (2012). Paediatric medical trauma: the impact on parents of burn survivors. Proceedings of the International Society of Burn Injuries Congress, August 2012, Edinburgh, Scotland.
6. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott C (2012). Paediatric health care professionals: relationships between psychological distress, resilience and coping. Proceedings of the International Society of Burn Injuries Congress, August 2012, Edinburgh, Scotland.
7. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott C (2012). Paediatric health care professionals: relationships between psychological distress, resilience and coping. Proceedings of the Western Australia Occupational Therapy Conference, October 2012, Perth, Australia.
8. **McGarry S**, Elliott C, McDonald A, Valentine J, Wood F, Girdler S (2013). 'This is not just a little accident': a qualitative understanding of paediatric burns from the perspective of parents. Proceedings of the British Burns Association Conference, May 2013, Liverpool, United Kingdom.
9. **McGarry S**, Elliott C, McDonald A, Valentine J, Wood F, Girdler S (2013). Paediatric burns: from the voice of the child. Proceedings of the British Burns Association Conference, May 2013, Liverpool, United Kingdom.
10. **McGarry S**, Elliott C, McDonald A, Valentine J, Wood F, Girdler S (2013). 'This is not just a little accident': a qualitative understanding of paediatric

burns from the perspective of parents. Proceedings of the Occupational Australia Conference, July 2013, Adelaide, Australia.

11. **McGarry S**, Girdler S, McDonald A, Valentine J, Wood F, Elliott C (2013). Paediatric medical trauma: the impact on parents of burn survivors. Proceedings of the Australia and New Zealand Burn Association Conference, October 2013, Perth, Western Australia.

Invited Presentations

1. Invited lecture on paediatric medical trauma for occupational therapy students at Edith Cowan University, April 2011, Perth, Western Australia.
2. Trauma Across the Lifespan Conference, November 2011, Perth, Western Australia.
3. Grand Round presentation at Princess Margaret Hospital, invited speaker for the Psychological Medicine Grand Round Session, 2011, Perth, Western Australia.
4. Invited lecturer for the Allied Health Forum held at Princess Margaret Hospital, 2011, Perth, Western Australia.
5. Invited lecture on paediatric medical trauma for Masters in Neurological Rehabilitation students at University of Western Australia, 2011, Perth, Western Australia.
6. Invited lecture on paediatric medical trauma for occupational therapy students at Edith Cowan University, May 2012, Perth, Western Australia.
7. Invited lecture on paediatric medical trauma for occupational therapy students at Edith Cowan University, April 2013, Perth, Western Australia.
8. Guest lecturer for Occupational Therapy Australia Webinar Series, September 2013, Perth, Western Australia.
9. Invited speaker on vicarious trauma in health professionals, at the Australia and New Zealand Burn Association Conference, October 2013, Perth, Western Australia.

Awards and Grants

- Faculty winner of the Three-Minute Thesis Competition 2010, Edith Cowan University.
- Inaugural recipient of the Gordon Barron-Hay Grant, 2012.
- Winner of the Health Professional Award, 2012 at the Child and Adolescent Health Research Symposium, Perth, Western Australia.

Invited Scientific Reviewer

- Reviewer for the Lancet
- Reviewed abstracts submitted for the Occupational Therapy WA Conference 2012
- Reviewed abstracts submitted for the upcoming Australia New Zealand Burns Association Conference 2013, October
- Selected to review abstracts submitted for the upcoming World Occupational Therapy Conference 2014, June

Clinical Experience

While completing my PhD, I worked as a Senior Occupational Therapist 0.2 FTE on the Total Care Burns Unit at Princess Margaret Hospital for Children.

Contents

Declaration.....	i
Abstract.....	ii
Acknowledgements	iv
Publications and Abstracts	vi
Contents	x
Chapter 1: Introduction.....	1
1.1 Introduction.....	1
1.2 Statement of the Problem	3
1.3 Thesis Outline.....	4
1.4 Significance of the Study.....	6
1.5 References.....	9
Chapter 2: Literature Review	10
2.1 Introduction.....	10
2.2 The Model of Paediatric Medical Traumatic Stress	12
2.3 Burn Injuries	18
2.4 Healthcare Providers Working Within a Hospital Setting	21
2.5 References.....	25
Chapter 3: Paediatric Burns: From the Voice of the Child	34
3.1 Abstract.....	35
3.2 Introduction.....	36
3.3 Findings.....	39
3.4 Discussion	52
3.5 Conclusion	56
3.6 References.....	58
Chapter 4: Paediatric Medical Trauma: The Impact on Parents of Burn Survivors	61
4.1 Abstract	62
4.2 Introduction.....	63
4.3 Method	66
4.4 Results.....	68
4.5 Discussion	68
4.6 Conclusion	72
4.7 References.....	73
Chapter 5: ‘This is Not Just a Little Accident’: A Qualitative Understanding of Paediatric Burns from the Perspective of Parents.....	77
5.1 Abstract	78
5.2 Introduction.....	79
5.3 Methods.....	80
5.4 Findings.....	82
5.5 Discussion	96
5.6 Conclusion	100
5.7 References.....	102

Chapter 6: Paediatric Healthcare Professionals: Relationships Between Psychological Distress, Resilience and Coping Skills	105
6.1 Abstract	106
6.2 Introduction	107
6.3 Method	109
6.4 Results	112
6.5 Discussion	120
6.6 Conclusion	123
6.7 References	125
Chapter 7: Limitations	128
7.1 References	129
Chapter 8: Conclusions and Recommendations	130
8.1 Overview	130
8.2 Discussion	131
8.3 Recommendations for Clinical Practice	135
8.4 Knowledge Translation	139
8.5 Recommendations for Future Research	141
8.6 References	143
References	146
Appendices	160
Appendix A: Published Manuscript—Paediatric Medical Trauma: The Impact on Parents of Burn Survivors	160
Appendix B: Ethics Approval	169
Appendix C: Child Qualitative Letter	172
Appendix D: Parent Qualitative Letter	175
Appendix E: Parent Quantitative Letter	178
Appendix F: Staff Quantitative Letter	181
Appendix G: Consent Form	184
Appendix H: Parent Assessment Battery	186
Appendix J: Staff Assessment Battery	203

List of Figures

Figure 2.1: The Paediatric Medical Traumatic Stress Model.....	13
Figure 3.1: Identified Themes	40
Figure 5.1: Identified Themes	83

List of Tables

Table 3.1: Colaizzi's (1978) Data Analysis Framework Procedure [11].....	39
Table 4.1: Sample Demographics of Parents	69
Table 4.2: Sample Description of Children.....	70
Table 4.3: Outcomes Compared to Population Reference Groups	71
Table 4.4: Mean Differences Between Mothers and Fathers	73
Table 4.5: Correlations (Spearman's rho) Between Outcome Variables	68
Table 5.1: Colaizzi's Data Analysis Framework Procedure [16]	81
Table 6.1: Sample Demographics Distribution of Gender, Age and Occupation	113
Table 6.2: Outcomes Compared to Population Reference Groups	114
Table 6.3: Outcomes by Age <25 and >=25 years.....	116
Table 6.4: Correlations (Spearman's Rho) Between Outcome Variables.....	118
Table 6.5: Correlations Between Coping Strategies and Psychological Factors	119
Table 6.6: Correlations Between Coping Strategies	119
Table 6.7: Linear Correlations Between Demographic Variables and Psychological Factors.....	120

Chapter 1: Introduction

1.1 Introduction

Burn injuries have been reported as one of the most painful and traumatising injuries an individual can sustain and are a serious global health threat to children [1]. Despite the magnitude of this public health problem, there is a paucity of research examining the underlying psychological burden associated with such injuries for children and for the parents and staff caring for these patients. With improvement in surgical outcomes and survival rates for burn survivors, the next aim is to minimise the subsequent development of negative psychological outcomes, thereby improving the quality of life for parents, families and patients.

Paediatric medical traumatic stress refers to the psychological and physical responses experienced by children and their families as a result of encountering pain, injury, serious illness, medical procedures and invasive and frightening treatment experiences [2]. The model of paediatric medical traumatic stress was developed to conceptualise the experiences of children and families within medical settings. The model conceptualises paediatric medical trauma as a continuous process accounting for paediatric medical traumatic stress at various phases within treatment and illness progression. The patient and family's experience of trauma is described as moving through three phases: Phase I, the occurrence of the potentially traumatic event; Phase II, early (acute), ongoing and evolving traumatic stress responses; and Phase III, longer-term traumatic stress responses [2].

Healthcare professionals are exposed to trauma on a daily basis, witnessing acute medical trauma, performing painful medical procedures and dealing with end-of-life scenarios. With the pressures associated with large, complex caseloads, health professionals are often unable to process their reactions and the effect this has on healthcare professionals' wellbeing is not well documented.

Children are often described as a vulnerable population in society. Paediatric health

professionals recognise this status and recognise that in the context of trauma, they may be at greater risk of experiencing psychological distress. With a growing national shortage of healthcare professionals, [3] it is vital that efforts are made to understand and explore factors affecting the psychological profiles of paediatric multidisciplinary teams. Health professionals play a critical role in the therapeutic relationship between children and parents. For this reason, it is important to investigate the implications of exposure to paediatric medical trauma on all three groups.

It is clearly established that parents and children experience symptoms of psychological distress after a burn injury. However, what remains unknown is the relationships that exist between psychological outcomes, the role of resilience and the lived experience of sustaining a burn from the point of view of the child and the parent. No research to date has explored the impact of paediatric medical trauma on children and parents in an Australian population, including either Aboriginal children or parents. The majority of research investigates the wellbeing of mothers and a need remains to document the wellbeing of fathers. Investigating the impact of paediatric medical trauma on children, parents and staff requires a multi-factorial approach that should be guided by a theoretical framework. However, to date, no research has validated the model of paediatric medical traumatic stress and this is required.

Mixed-method research increases the breadth and depth of understanding of a topic by capitalising on the strengths of both qualitative and quantitative methodologies. Using both quantitative and qualitative methodologies in this study provides a comprehensive understanding of the theoretical model, as each method can uncover unique findings that otherwise may be neglected when using a single methodology. Additionally, qualitative findings expand and elaborate on numeric trends identified by the quantitative research, and aim to develop converging lines of inquiry. Therefore, findings from this research project will provide unique, new knowledge in this field.

1.2 Statement of the Problem

This research provides a unique contribution to the field of paediatric trauma, as many researchers have expressed concern for the lack of rigorous research in traumatic stress outcomes in the field of paediatrics [4, 5]. Most research has been limited to observational studies and these research designs lack comparison groups, making them particularly vulnerable to threats of internal validity. Additionally, the model of paediatric medical traumatic stress has not been validated and this study will aim to do so by using both qualitative and quantitative techniques to provide a thorough understanding of this theoretical framework.

Due to the limited research in this area, there are many unanswered questions and inconclusive results regarding risk factors associated with traumatic stress symptoms and the relationships between adverse psychological symptoms and resilience in paediatric burn populations. This study will provide insight into prevalence rates of symptoms of post-traumatic stress disorder (PTSD), depression, anxiety, stress and resilience in the parents and staff in a paediatric hospital, compared to the general population. This is the first Australian study to examine paediatric burns trauma in comparison to the general population, investigating several psychological outcomes including resilience levels and simultaneously investigating the three key stakeholders critical to the therapeutic relationship: children, parents and staff.

The majority of research in this area is based on US populations and researchers have documented a need for future studies investigating acute and long-term traumatic stress symptoms in children and parents from diverse populations and settings [5]. The population sample in this research is unique, compared to other samples previously investigated, on account of the high proportion of Aboriginal Australians and families residing in rural and remote communities. Additionally, the present sample includes fathers, an under-represented group in the literature. To ensure a holistic and comprehensive understanding of psychological distress in children and parents, it is important for diverse populations to be investigated.

Qualitative research investigates people as they exist, within their natural contexts and

the meanings, experiences and perceptions they attach to this context. To our knowledge, no research has qualitatively explored the model of paediatric medical traumatic stress in a paediatric burns population. An understanding of the lived experience from the point of view of the child and parent is required to provide a deeper perceptive and understanding of paediatric medical traumatic stress. This, in turn, will lead to the development of service delivery plans, guided from the lived experience of patients and their parents. Improvements in medical advances mean survival rates and physical outcomes for children with burns have improved. However, it is vital that the underlying psychological outcomes are investigated at a rate to match these developments, and benefit not only children but also their parents and the staff caring for these families.

1.2.1 Study Aims

This study aims to describe the multi-factorial impact of paediatric trauma on children, parents and staff within an Australian children's hospital. The secondary aims of this study were to identify individuals at risk of developing adverse psychological outcomes and the relationship between psychological outcomes and demographic factors. It seeks to determine if the model of paediatric medical traumatic stress is suitable for an Australian population, and to explore the lived experience of sustaining a burn from the perspective of both the child and the parent.

1.3 Thesis Outline

The introduction and literature review provide a context for the study and communicate the research problem and approach taken to answer the research questions. The thesis is presented as a series of individual papers addressing four separate but interrelated studies. The thesis concludes with a synthesis of results and discussion.

1.3.1 Chapter 3, Paper 1: Paediatric Burns: From the Voice of the Child

The aim of this paper is to:

- explore the experience of children with burn injuries from the child's perspective.

As this paper utilises a qualitative methodology, no specific hypotheses are presented, but rather a research question:

- What is the lived experience of sustaining a burn from the child's perspective?

1.3.2 Chapter 4, Paper 2: Paediatric Medical Trauma: The Impact on Parents of Burn Survivors

The aim of this paper is to:

- investigate the impact of exposure to paediatric trauma on parents of children with a burn and to identify risk factors and relationships between psychological distress and resilience.

It is hypothesised that:

- the psychological profiles of parents exposed to paediatric medical trauma are less optimal than controls
- pre-existing factors are associated with psychological responses in parents
- relationships exist between symptoms of psychological distress and resilience.

These hypotheses were investigated within the total population sample and sub-populations of gender and Aboriginality.

1.3.3 Chapter 5, Paper 3: *'This is Not Just a Little Accident': A Qualitative Understanding of Paediatric Burns from the Perspective of Parents*

The aim of this paper is to:

- describe the experiences of parents of children admitted to hospital for a burn.

As this paper utilises a qualitative methodology, no specific hypotheses are presented, but rather a research question:

- What is the experience of parents of children admitted to hospital for a burn?

1.3.4 Chapter 6, Paper 4: Paediatric Health Care Professionals: Relationships Between Psychological Distress, Resilience and Coping Skills

The aims of this paper are to:

- investigate the impact of regular exposure to paediatric medical trauma on multidisciplinary teams in a paediatric hospital
- investigate the relationships between psychological distress, resilience and coping skills.

It is hypothesised that:

- there is a difference between the current psychological profiles of healthcare professionals and that of comparison groups
- pre-existing factors are associated with psychological responses in health professionals
- relationships exist between symptoms of psychological distress, resilience and coping strategies.

1.3.5 Chapter 7: Synthesis of Results and Conclusions

The final chapter aims to provide an overall synthesis of findings presented throughout the thesis, integrating the major findings from each study and providing an overall conclusion of the research in its entirety. This chapter also outlines recommendations for future research, clinical practice and translation of research.

1.4 Significance of the Study

This research has the considerable potential to influence clinical practice and enhance clinical outcomes for individuals following traumatic events for several reasons. Through identification of influential factors occurring within the pre-trauma phase, it will be possible to identify children, families and staff who are at greater risk of developing psychological distress. This is important, as it may lead to the early identification of acute stress in those at risk, which can be addressed with the aim of reducing the development of long-term adverse psychological outcomes.

Identification of children, families and staff at risk is also important for resource management, as resources can be focussed on parties in greatest need. Overall, this research has the potential to influence service delivery within paediatric hospitals. Identification of risk factors for psychological distress will enable improved health outcomes and a reduction in illness that will enhance the quality of care of Australian children and their families.

Further, this research will facilitate a greater understanding of the application of the paediatric medical traumatic stress model as a theoretical framework. It will add to the existing knowledge base by exploring the effectiveness of the model within an Australian population, and will aim to validate the model. This research is unique in utilising both qualitative and quantitative methods. Investigating the lived experience of children with burns and their parents provides an in-depth understanding of this phenomenon, which might not otherwise be uncovered by objective outcome measures. This data will provide a voice for burn survivors and their families and guide service delivery, taking into account consumers' needs and perspectives, as described by the individual.

Research concerning the prevalence of vicarious trauma and psychological distress among paediatric medical professionals is scarce. Given the impact paediatric trauma can have on quality of life, it is vital to investigate if paediatric trauma has an effect on staff wellbeing and psychological functioning. Results from this study are important as they may influence changes to clinical caseload and workplace practices, contributing to increased staff retention and wellbeing.

Identifying psychological symptoms experienced by staff may reduce loss in productivity caused by sick leave, absenteeism, early retirement and time spent on recruitment and training due to increased staff turnover. With an increasing population and shortages in healthcare professionals, it is important that hospitals endeavour to implement strategies to retain their employees [3]. This research will contribute to key objectives set by the Australian Government regarding paediatric hospitals, which include aiming towards a skilled and competent workforce responsive to future demands, providing safe and high-quality services, using evidence to inform consistent service delivery across the metropolitan area and being recognised as a

leader in the provision of child and adolescent community health services [6].

Symptoms of psychological distress pose a significant threat to the physical and psychological functioning of individuals. This study aims to uncover risk factors associated with adverse psychological outcomes, to describe the lived experience of children and parents and facilitate the recognition of individuals at risk. Findings from this study have the potential to maximise the quality of life in children, parents and health professionals. To provide effective interventions to address the outlined problems, data describing the phenomena and its relevance to an Australian paediatric hospital must first be collected. There is a need for health professionals and families to gain a greater understanding of paediatric trauma for both therapeutic interventions and increased health outcomes.

1.5 References

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Chapter 2: Literature Review

This literature review initially outlines each section of the paediatric medical traumatic stress model in relation to all paediatric injury and illness. This is followed by a discussion specific to burn injuries. Finally, the implications of exposure to paediatric medical trauma on health professionals who work within paediatric hospitals are discussed.

2.1 Introduction

More than 2000 children die every day as a result of unintentional or accidental injuries [1]. Additionally, tens of millions of children worldwide survive accidental injuries and require hospitalisation. For many of these children, lifelong disability results from their injury [1]. The leading causes of such injuries to children are road traffic crashes, burns, drowning, falls and poisoning [1]. These injuries are preventable and affect not only the child but their family, friends and community [1]. In addition to inflicting physical injuries, these accidents can also have an adverse psychological influence on an individual and their family.

Paediatric medical traumatic stress refers to both the psychological and physical responses experienced by children and their families as a result of encountering pain, injury, serious illness, medical procedures and invasive and frightening treatment experiences [2]. It is reported that 74.9 per cent of Australians have been exposed to at least one traumatic event in their life [3]. Given these statistics, it is unsurprising that PTSD is one of the most common anxiety disorders with approximately 250,000 Australians diagnosed at any given time [4]. Research shows that the majority of trauma survivors are not screened or treated for post-traumatic psychological problems, suggesting that PTSD in the wider community may be under-diagnosed [5]. Active symptoms of PTSD have been found to endure for an average of 20 years and can negatively impact quality of life, physical recovery and functioning [6–9]. Psychological trauma resulting from a traumatic event has been described as a significant public health issue [9]. The pervasive effect of trauma

on a person's life and associated healthcare costs necessitates best-practice assessment and intervention.

Traumatic stress responses are characterised by a three-symptom cluster: intrusive re-experiencing of the trauma, avoidance and hyperarousal [10]. For a diagnosis of PTSD, symptoms from each of these clusters must persist for one month or longer [10]. Acute stress disorder (ASD) has been a useful diagnosis for assessing the distress of individuals exposed to trauma within the first month post-trauma [10]. The diagnosis of ASD differs from PTSD principally in the time frame of symptoms. However, ASD also involves a cluster of dissociative symptoms [10]. Dissociative symptoms are described as alterations in memory (e.g. aspects of the trauma not consciously accessible), in identity (disengagement between self and environment) and in consciousness [11].

Many individuals experience distress post-trauma but do not meet the full *Diagnostic and Statistical Manual for Mental Disorders IV* (DSM-IV) criteria for a diagnosis of ASD or PTSD [12, 13]. The assessment of symptoms of ASD and PTSD in children and parents has proven to be a more useful and thorough approach in assessing individuals at risk [12, 13]. In the literature, many researchers favour the use of screening tools to assess symptoms of ASD and PTSD, rather than diagnostic assessments [14–16]. Limiting reports of findings to those of individuals diagnosed with PTSD may overlook numerous individuals experiencing significant psychological distress.

Frequently, researchers have stressed the importance of investigating rates of depression and anxiety when examining symptoms of ASD and PTSD [17, 18]. Data from population-based studies suggest the majority (79 per cent to 88 per cent) of individuals with PTSD will experience psychiatric co-morbidity [4]. Commonly occurring co-morbidities to ASD and PTSD include anxiety, depression and substance abuse [4]. However, PTSD symptoms are unique, as research indicates overlapping anxiety and mood disorder symptoms do not account for the prevalence, diagnostic co-morbidity and construct validity of PTSD [19]. To date, no research has investigated resilience levels in parents exposed to paediatric medical trauma, or what relationships exist between resilience and adverse psychological outcomes.

Resilience is the capacity to positively adapt and cope despite adversity [20] and has been described as an innate psychological immune capacity, which may be an underestimated concept that is missing in trauma literature [21, 22]. It has been suggested that to completely understand dysfunction as a result of trauma, a greater awareness of resilience is required [21]. Examining the role of resilience in parents is important to explain why some families cope better with the psychological effect of paediatric medical trauma. This understanding will be beneficial for developing strategies to assist families in the future.

2.2 The Model of Paediatric Medical Traumatic Stress

The model of paediatric medical traumatic stress was developed to conceptualise the experiences of children and families within medical settings [13]. The model was developed based on clinical and research work conducted to understand the experience of children and families [13]. This model conceptualises paediatric medical trauma as a continuous process accounting for paediatric medical traumatic stress at various phases within treatment and illness progression [13]. A central tenet of the model is that it considers the child in the context of the family, reflecting the shift towards family-centred service delivery [23]. The patient and family's experience of trauma are described as moving through three phases: immediate, acute and long-term (see Figure 2.1) [13]. The duration of these phases is not defined and may not correspond to those defined by the DSM-IV criteria for ASD and PTSD. This model differs from other models of acute stress response as it considers characteristics of the event in both a subjective and objective manner and incorporates both child and parent experiences [13]. To date this model has not been tested in practice or validated.

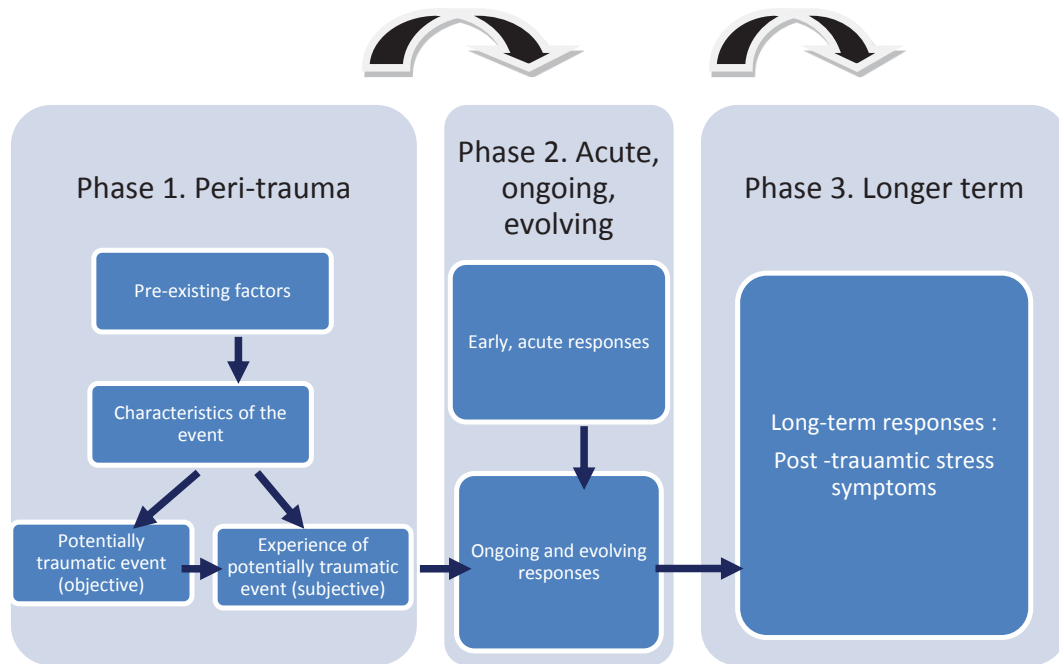


Figure 2.1: The Paediatric Medical Traumatic Stress Model [13]

2.2.1 Phase 1: Peri-Trauma

This phase acknowledges pre-existing factors an individual brings to the experience of trauma. Pre-existing factors can influence an individual's vulnerability to becoming susceptible to adverse psychological symptoms. Characteristics of the event are another important factor in this phase, as are objective measures of the severity of the potentially traumatic event. Included in this phase is the importance of the individual's subjective experience of the potentially traumatic event.

2.2.1.1 Pre-existing Factors

Pre-existing factors can contribute to the perception of an event as traumatic and to the subsequent development of PTSD symptoms [13, 16]. Growing evidence suggests that younger age, female gender and a history of trauma are among the most significant risk factors for the development of ASD and PTSD in children and adults [16, 8, 24, 25, 26]. Additionally, a history of mental illness and low pre-morbid social support increases the likelihood of poor psychological adjustment post-trauma [7, 27, 28].

In children, risk factors associated with PTSD include prior behavioural or attention problems, not living with biological parents and lower parental education [29, 30]. Research suggests excessive parental control, family conflict and parental over-protectiveness are family factors associated with PTSD symptoms in adolescents [31]. Further, perceived lack of support from parents has been reported to be positively related to higher levels of distress in children and adolescents [31]. There is a need for the early identification of at-risk children and parents [32], which would aim to provide early services for those patients and families who require it most.

2.2.1.2 Characteristics of the Event

Peri-traumatic factors known to influence the development of PTSD include perceived life threat during the traumatic event, severity of exposure to the trauma, emotional response during the event and signs of post-traumatic hyperarousal, such as an elevated heart rate [16, 27, 33]. For children, exposure to others injured at the same time and separation from parents at the time of injury can increase the likelihood of PTSD symptoms [16]. It is important that health professionals gain a thorough understanding of the characteristics of a traumatic event to identify those individuals at risk of developing ASD or PTSD.

2.2.1.3 Objective Experience of the Event Compared to the Subjective Experience of the Event

Evidence suggests that the subjective experience of an event has a significantly greater effect on whether it is perceived as traumatic than objective measures of the event itself [15, 34–36]. To be considered traumatic, an event must provoke feelings of life threat, fear, horror and helplessness in an individual [10]. If this does not occur, it is suggested that it is unlikely an individual will experience psychological consequences related to the event [35].

A study in Japan confirmed these assumptions when examining the impact of objective measures of potentially traumatic motor vehicle accidents (MVAs) with psychological *sequelae* following MVAs (n=49) [36]. The Injury Severity Score, barrier equivalent speed and change in velocity during impact were used to objectively measure the physical

severity of the accident. Findings revealed that these measures did not correlate with PTSD symptoms or psychiatric symptoms, five and 14 months post-MVA [36]. However, subjective measures such as perceived life risk and persistent medical problems were related to psychological *sequelae* [36]. This highlights the need for health professionals to screen individuals who have experienced potentially traumatic events, using both objective measures and standardised subjective measures of the event. Qualitative research aims to further explore an individual's subjective experience, providing a greater understanding of the concept.

2.2.2 Phase II: Early, Ongoing and Evolving Responses

Phase II accounts for the acute stage where children and parents experience early, ongoing and evolving responses to paediatric medical trauma. During this phase, the child's medical condition and continuous treatment provide many stressors and challenges for patients and their families [13]. Adverse psychological responses at this stage have the potential to affect health outcomes as patients and their families may not adhere to treatment regimens and may experience negative responses to procedures and pain [13].

High prevalence rates of ASD and PTSD are reported in both children and parents during this phase, highlighting the impact trauma can have on an individual's emotional and psychological responses. It is estimated that approximately 80 per cent of children and parents report at least one ASD symptom within the first four weeks after a child's traumatic injury [37]. Research investigating ASD symptoms in children and parents is increasing, with the majority of research conducted in the United States, displaying a prominent focus on maternal wellbeing. Future research is required to assess symptoms of traumatic stress within more culturally diverse medical populations and settings, including regional and rural populations. Differences between gender and culture also require further investigation.

It has been reported that parents' and children's perception of symptomatic and functional recovery after traumatic injury often differ and that parents are not reliable in reporting their child's symptoms [38–40]. Evidence suggests that parent and nurse reports used to measure ASD symptoms in children and adolescents may underestimate the real rates of ASD symptoms experienced by young patients [27, 38]. In a sample of 54 youths

admitted to hospital for injuries, 93 per cent reported symptoms of ASD on the Traumatic Events Screening Inventory for Children [27]. In comparison, only 65 per cent of parents reported their children as experiencing ASD symptoms on the Child Stress Reaction Checklist [27].

Supporting these findings, a prospective study collecting both parent and child reports found that only considering parental reports may have resulted in three-quarters of the child participants who had ASD symptoms remaining undiagnosed [41]. In contrast, it has been reported that parents and children with burn injuries do not differ in their reporting of functional and psychosocial recovery after a burn injury [42]. However, this study focusses more on functional recovery and does not measure symptoms of ASD [42]. These findings have led many researchers to encourage future research, where possible, to consider both the child's self-report, as well as the parental report of the child's symptoms [38–41].

It is important to acknowledge that reactions of distress from parents and children after a traumatic accident are a normal response [13]. In some cases, these reactions can be beneficial, as they may serve to help parents adapt and grieve during this acute phase [13]. However, evidence suggests that once the symptoms persist and begin to affect daily functioning, responses can no longer be considered normative and early identification and intervention is imperative [13].

2.2.3 Phase III: Long-Term Responses

Phase III includes the long-term experiences and traumatic stress responses of children and parents. In many cases, traumatic responses do not subside after the initial, acute phase. Often, once patients and families are discharged from hospital and in their home environment, symptoms can become more distressing [13]. Families' emotional responses change as their everyday lives may become drastically different as a result of the accident. Daily routines, roles and occupations may have to be altered from life before the accident.

Estimates of the prevalence of post-traumatic stress symptoms among children hospitalised for trauma- or injury-related admissions ranges from six to 45 per cent [16, 43]. The discrepancy in numbers of prevalence is largely due to different sample

characteristics and varying measurement tools used in a number of independent studies. Children admitted to hospital for non-trauma-related issues experience lower rates of symptoms of PTSD than those admitted due to a traumatic event [43]. Acute PTSD symptoms experienced in hospital have a negative impact on health and function across time [7]. In addition to children, it is estimated that between nine to 47 per cent of parents of children requiring hospitalisation due to a traumatic injury experience symptoms of PTSD [15, 16, 44, 45]. This data suggest both parents and children are susceptible to symptoms of PTSD and highlights the impact trauma can have within a family.

In adults and adolescents, the functional impact of PTSD is linked to negative health behaviours and poor health outcomes. Negative health behaviours include increased rates of smoking [25] and substance abuse [46, 47]. Symptoms of PTSD have been demonstrated to have a negative impact on family relationships, are associated with decreased life satisfaction [8, 48] and an increase in use of mental health resources [8]. Additionally, when compared to demographically matched controls, individuals with PTSD are six times more likely to attempt suicide [49]. Further, PTSD has been found to have a stronger relationship with suicidal ideation than all other anxiety disorders [49].

The onset of PTSD has not only been linked with detrimental functional outcomes, but also with poor physical health outcomes [50, 51]. Individuals experiencing PTSD symptoms have an increased likelihood of experiencing cardiovascular ailments [52] and increased levels of disability [9, 51]. PTSD is associated with increased rates of healthcare utilisation, medical and psychiatric adversity and results in more non-specific health complaints [39, 50]. Poor psychological adjustment after experiencing trauma is associated with a significant detrimental impact on an individual's life, highlighting the value of early screening and treatment for individuals at risk of developing PTSD.

Research investigating the impact of PTSD in children has found that it can negatively affect developmental outcomes [53, 54]. It has been suggested that developmental processes in adolescents and children may alter the meaning of past medical experiences [53–55]. This has been demonstrated in studies comparing the rates of symptoms of PTSD in adolescents and children at various ages. Young adults who survived cancer as a child are more likely to exhibit PTSD symptoms when compared to children with cancer [53, 55]. Whereas children who survived a motor vehicle accident report a higher

likelihood of ASD symptoms than adolescents [56]. Therefore, it is implicit a child's or an adolescent's developmental stage be considered when assessing and intervening for post-trauma symptoms [13, 54].

2.3 Burn Injuries

Research has begun to document the psychological outcomes of children who have experienced a burn. Findings provide preliminary evidence to indicate pre-existing factors and characteristics of the burn event influence psychological outcomes in children and parents, and that acute and long-term symptoms of adverse psychological outcomes are present [57].

Pre-existing factors known to influence acute stress symptoms in school-aged children with burns include a younger age [58], female gender [59, 60] and greater previous life stressors [61]. Risk factors reported to influence parent symptomatology include being a mother [24], age (younger) [62], having ineffective coping strategies [63], family conflict [45], poor family functioning and lower emotional stability prior to the event [62]. These findings provide initial evidence for the role of pre-existing factors in influencing psychological outcomes, although further research is required.

Studies investigating burn injuries have determined that characteristics of the event can influence adverse psychological outcomes in children. Hot water burns have been shown to predict lower quality of life in children compared to flame burns [64] and children with facial burns and/or hand burns experience more psychosocial concerns than children without burns to their face or hands [65, 66]. Greater pain experience is known to influence symptoms of PTSD [58] and research investigating young children aged 12 to 48 months old suggests the size and severity of the burn influences post-traumatic stress symptomatology [67]. This has also been found to be the case in school-aged children [61, 64]. However, in contrast to these findings, studies have shown no relationship between burn characteristics and adverse psychological outcomes in children at the time points of three months, six months and one to 13 years post-burn [68–70].

Similar contrasting results have been found in research investigating parents. Recent research reports variables such as size of the burn, days spent as inpatient, or parental presence at the time of the burn were not related to parental distress [71]. However, other studies have found that burn size and severity contribute to acute stress symptoms in both mothers and fathers [24, 45, 72]. The discrepancies in these results may be due to differences in the outcome measures used and the burn populations investigated.

A recent critical review of the psychological consequences of paediatric burns concluded that between 25 to 30 per cent of preschool children experience significant traumatic stress reactions during the acute phase (less than one month) after sustaining a burn [57]. These symptoms have also been shown in one-third of school-aged children who sustained a burn [57]. Parents of children with burn injuries experience clinically significant symptoms of PTSD in the acute phase (one to four weeks post-burn) with rates reported between 18.8 per cent [73] to 50 per cent [24].

A synthesis of the literature on the long-term psychological effects of burn injuries suggests that between ten to 20 per cent of school-aged children have reported symptoms of PTSD, several years after the event [57]. At three months post-burn, 47 per cent of parents have been reported to experience clinically significant post-traumatic stress symptoms [45]. Symptoms have been shown to persist in some parents, with data suggesting 17 per cent of parents experience PTSD up to seven years post-burn [74]. These results highlight the long-lasting impact PTSD can have on the lives of burn survivors and their families.

Anxiety and depression have also been reported to occur in parents of children who sustained a burn, with rates of symptoms varying from 18.8 per cent [73] to 69.9 per cent [62]. In children, rates of depression appear to be variable. It has been reported that children experience no symptoms of depression several weeks after the burn [73]. However, symptoms of major depression have been found to be present in three per cent of children nine years after a burn [75] and in nine per cent of young adults 14 years after the event [60]. However, research including normative control groups has found no difference between symptoms of depression in children with burns compared to children in the general population [59, 78].

Internalising problems such as feeling anxious and withdrawn have been found in 22 to 25 per cent of children in the acute phase after a burn [76] and in the majority of children assessed in a sample in Spain [77]. Anxiety has been shown to persist in approximately five to 37 per cent of children in the long-term phase after a burn injury [76, 78–80]. Clearly, children and parents of children who have sustained a burn experience significant psychological distress and require support during this time.

It is evident that burn injuries affect both the patient and their families. While there is an emerging body of research describing prevalence rates of psychological distress in children with burn injuries and their parents, qualitative research describing the lived experience of children with burns and their parents is scarce. Qualitative research can provide rich information on phenomena that otherwise may not be uncovered by objective measures [81]. To date, qualitative research has focussed on parents' perception of their child's return to school [82], family functioning [62] and children's experiences of attending burn camps [83, 84].

The only research to describe the experience of sustaining a burn was one, small qualitative study in South Africa that explored the processes of identity negotiation in nine young adults (with a mean age of 19 years). This study provides insight into resilience in young adults with burns, particularly within the context of a low income, Native African population residing in South Africa [85]. Research investigating the lived experience of children is required to further understand the experience, needs and stressors from the child's perspective.

Three qualitative studies have explored parents' experiences of having a child with a burn [86–88]. Two of these studies are very recent and investigate populations in Iran and India, providing useful information on how culture can influence parental experiences [86, 87]. The study conducted in Iran provides valuable information on common misconceptions about burns first aid and treatments unique to an Iranian population [86]. Whereas the study exploring Indian parental experiences describes how Indian parents embraced survival, experienced trauma symptoms alongside their child, protected their child from cultural stigma and faced challenges associated with living in a low income country, such as difficulty accessing medical treatments [87].

Another qualitative study conducted with parents of children with burns was conducted over two decades ago [88]. This study describes the experiences of mothers in the UK and identified a maternal response pattern [88]. This pattern involved three stages including: Phase I—continuing emotional trauma; Phase II—attempting to rationalise; and Phase III—rationalisation of the thermal injury [88]. Although findings from this study may be out-dated due to advances in medical treatments over the past two decades, it provides insight into the experiences of mothers, which is an under-researched phenomenon. These qualitative studies provide valuable information and enhance existing understanding of paediatric burns. However, there is a need for similar studies to expand this work with parents across other cultures using strong, qualitative methodologies.

Although the model of paediatric medical traumatic stress has been referenced in numerous studies, particularly those involving children with a cancer diagnosis [89–91], it has not been validated. Future research investigating diverse paediatric populations in different locations is required to validate the theoretical and cultural application of the model. As outlined, many unanswered questions remain regarding paediatric medical trauma and, in particular, how it affects paediatric burns populations. There is a need for future quantitative and qualitative studies to address the gaps outlined in the literature.

2.4 Healthcare Providers Working Within a Hospital Setting

Healthcare professionals are exposed to trauma on a daily basis, witnessing acute medical trauma, performing painful medical procedures and dealing with end-of-life scenarios. With the pressures associated with large, complex caseloads, professionals often struggle to process their reactions [92]. The effect this has on the wellbeing of healthcare professionals is unclear. Healthcare professionals working with traumatically injured adults are at increased risk of experiencing negative psychological effects [93–95], although research investigating the wellbeing of multidisciplinary teams within paediatric hospitals is scarce. Children are often described as a vulnerable population in society. Paediatric health professionals recognise this status, and recognise that in the context of trauma, they may be at a greater risk of experiencing psychological distress. With a growing national shortage of healthcare professionals [96, 97] it is vital that efforts are

made to understand and explore the factors affecting the mental health of paediatric multidisciplinary teams.

Various terms have been used to describe the effects of occupational exposure to another person's trauma: 'secondary traumatic stress', 'compassion fatigue', 'vicarious trauma' and 'burnout'. These terms refer to the cumulative effects of exposure to trauma, each covering a subtly different concept [98]. Secondary traumatic stress (STS) is the occurrence of emotional responses and symptoms associated with working with patients who have experienced trauma [98, 99]. Symptoms of STS are similar to those of PTSD and may include fear, sleep difficulties and avoidance of intrusive clinical images [99]. The term 'STS' is sometimes used interchangeably in the literature with the term 'compassion fatigue' [98], but compassion fatigue differs slightly, as it also relates to the inability to provide empathy towards patients. In contrast, 'compassion satisfaction' describes the positive feelings associated with helping and caring for patients [98]. 'Burnout' refers to emotional exhaustion, depersonalisation and a decreased sense of accomplishment with professional tasks [100]; it is not specific to trauma work and can occur in any profession.

The concepts of STS, compassion fatigue, vicarious trauma and burnout have received growing attention in research. However, their effect in relation to working within a paediatric hospital has received little attention. A notable exception is the work of Robins, Meltzer and Zelikovsky [95] who investigated the impact of routine occupational exposure to traumatic aspects of child illness, injury and medical treatment on healthcare providers (n=314) within the Children's Hospital of Philadelphia [95]. Results showed that 39 per cent of staff demonstrated moderate to extremely high risk for compassion fatigue, while 21 per cent experienced moderate to high risk for burnout [95]. Increased length of employment and blurring of caregiver boundaries were predictive of increased rates of burnout and compassion fatigue within this sample [95]. However, noted limitations of this research involve the selection of a non-normative comparison group consisting of trauma workers such as volunteers, Red Cross staff and trauma professionals. It is difficult to draw conclusions based on the comparison group used, as levels of trauma exposure varied significantly between all participants. Additionally, the authors advise the risk of over-interpretation of their data, suggesting that although a statistical difference between the two groups was demonstrated, there may not be a

clinically meaningful difference due to multiple comparisons performed within the data [95]. This research has contributed important findings and knowledge to an under-researched area. However, it may not be appropriate to generalise these research findings to other cultures and environments.

Pre-existing factors can render health professionals more vulnerable to the subsequent development of adverse psychological effects. Female gender, third-year registrars and health professionals living alone or not in a relationship have been reported as at greater risk of developing intensified symptoms of burnout [96, 101]. Further investigation into pre-existing factors is required to develop screening tools aimed at identifying individuals at greatest risk. In developing interventions to maintain psychological health, there is a need to understand the potential barriers and facilitators to developing psychological distress and maximising optimal psychological health.

High levels of personal stress have been significantly associated with higher levels of clinical stress and compassion fatigue in paediatric healthcare providers [82]. In comparison, professionals who report low stress levels also report utilising more productive coping and self-care strategies [82]. In a qualitative research sample of 20 paediatric nurses, coping strategies such as exercise, meditation and journaling were reported as critical in managing symptoms of burnout and compassion fatigue [102]. However, little research in this area has evaluated interventions aimed at improving staff wellbeing and coping mechanisms. Initial evidence for educational programs focussed on positive self-care strategies for paediatric healthcare professionals have been documented in the US [82, 103] and a recent study has published guidelines for peer support in high risk organisations [104]. However, further research with standardised outcome measures is required.

Other studies in this area have focussed on a single aspect of exposure to trauma, such as symptoms of STS, burnout or compassion fatigue in one professional group (principally nurses), rather than evaluating a multidisciplinary team. To understand the magnitude of the problem, it is necessary to build on this evidence by gaining insight into prevalence rates in multidisciplinary teams of several facets of sub-optimal mental health, including depression, anxiety and stress and by examining the relationship between these factors.

‘Resilience’ refers to the capacity to positively adapt and cope despite adversity [20]. To date, no research has explored the role of resilience in buffering against psychological distress in multidisciplinary teams within paediatric hospitals. This concept has been identified as an area for future research, particularly in paediatric oncology nursing literature [105]. It is important to understand if resilience and positive coping strategies play a role in minimising the impact of exposure to paediatric medical trauma and whether these factors influence an individual’s vulnerability to psychological distress.

A recent randomised control trial demonstrated that providing resilience training two weeks prior to individuals being exposed to a video of a car accident was more effective in reducing feelings of distress, compared to individuals who received training regarding practical information on what to do in the event of a car accident [106]. Although this study was not conducted in a clinical setting, it provides initial evidence to suggest resilience training may be of benefit for paediatric health professionals. This knowledge would underpin the development of interventions for health professionals working in paediatric multidisciplinary teams. Increasing staff wellbeing has the potential to lead to better health outcomes, increased productivity and reduced staff turnover rates.

Further research investigating the psychological impact of paediatric medical trauma on health professionals may assist in developing organisational systems to facilitate optimal mental health and coping strategies in health professionals, thereby reducing sick leave, absenteeism, and early retirement, resulting in the maintenance of a healthy workforce and ameliorating shortages of health professionals.

Given the prevalence of paediatric trauma and its relevance to public health, assessing adverse psychological outcomes in children, parents and staff in paediatric hospitals is critical to improving long-term outcomes. There is a need to develop a greater understanding of the impact of paediatric trauma in a hospital setting and the relationship between patients, families and staff. This will improve the wellbeing of both families and healthcare professionals.

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Chapter 3: Paediatric Burns: From the Voice of the Child

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Foreword

Research investigating the child's lived experience of sustaining a burn has not been previously documented. The first study included in this thesis is a qualitative paper using phenomenology as a methodological approach to investigate the lived experience of children with burn injuries. In doing so, this paper aims to contribute to the research by documenting the voices of child survivors, providing an improved understanding of paediatric burns from the child's perspective. Information describing the burn journey throughout all phases from the burn event through to discharge into the community will improve evidence-based care by guiding clinical interventions.

3.1 Abstract

Introduction: Despite burn injuries being common in children, research into the psychological experience and trauma remains limited. Improvements in the professional understanding of children's experiences will assist in improving holistic care.

Purpose: This study uses phenomenology, a qualitative methodology to explore the psychological experiences following a burn injury in children.

Methods: In-depth interviews were conducted six months post-burn with 12 (six female and six male) children who required surgery for a burn injury. The children were aged eight to 15 years old. The interview examined the overall experience of children and included probing questions exploring participants' perceptions, thoughts and feelings. Transcripts were analysed according to the seven-step Colaizzi method. Relationships between themes were explored to identify core concepts.

Results: The findings demonstrated that trauma was central to the burn experience and comprised two phases: the burn trauma and the recovery trauma. Six themes emerged as a result of this experience: ongoing recurrent trauma; returning to normal activities; behavioural changes; scarring-the permanent reminder; family functioning and adaptation.

Conclusion: This research has clinical implications as its findings can be used to inform clinical care at all stages of the burn journey. These research conclusions could be used to develop comprehensive information and support management plans for children. This would complement and support the surgical and medical treatment plan, providing direction for comprehensive service delivery and improved psychosocial outcomes in children.

3.2 Introduction

Burn injuries have been described as one of the most painful injuries a person can experience and are a serious global health threat to young children [1]. In addition to the wound itself, children experience surgery, invasive, frightening medical procedures, and are often left with permanent scarring that may require future reconstructive surgery. Burn injuries can affect an individual's wellbeing physically, psychologically, socially and functionally.

It has been clearly documented that paediatric burns affect the wellbeing of both children and their families [2]. A recent critical review of the psychological consequences of paediatric burns concluded that between 25 to 30 per cent of preschool children experience significant traumatic stress reactions during the acute phase (less than one month) after sustaining a burn [2]. Acute stress symptoms include symptoms of avoidance, hyperarousal and re-experiencing of the event [3]. These symptoms have been demonstrated in one-third of school-aged children. Ten to 20 per cent of school-aged children report symptoms of PTSD several years after the event [2]. Family and social functioning is also impaired in children with burns, but understanding is limited and there is a need for further research investigating issues of body image, coping with burn-related trauma and social life, including bullying at school [2].

Qualitative research allows the child's experience to be explored, adding an enhanced understanding of concepts not assessed by standardised measures. To date, qualitative research has focussed on children's perceptions about burns camps [4, 5]. An innovative qualitative study in South Africa explored the processes of identity negotiation in nine young adults (with a mean age of 19 years) with burns, providing insight into resilience in young adults with burns [6]. More phenomenological studies investigating children's experiences of the burn journey throughout all phases from the burn event through to discharge into the community would improve understanding and expand care provision. While it is recognised children are embedded in a family context and this should be the focus of future research, the aim of this study was to provide an understanding of the phenomenon of the child's experience of a burn injury from their perspective. Future research investigating the parent's experience is required.

This study aimed to explore the experience of children with burns. In doing so, it aims to contribute to research by documenting the voices of child survivors, providing an improved understanding of paediatric burns from the perspective of school age children six months post burn.

3.2.1 Methods

Phenomenology was chosen as the most appropriate methodology for this study, as it allows the subjective experience of a phenomenon to be explored [7, 8]. This is useful when limited information is known about a specific phenomenon [8]. Phenomenological approaches allow the researcher to investigate the perceptions and the lived experience of a phenomenon and the associated meanings through in-depth analysis of individual's subjective experiences [8]. Phenomenology has been validated as a qualitative method appropriate for use with child participants [9].

3.2.2 Data Collection

A purposive sample of 12 children who sustained a burn injury requiring surgery was recruited [7]. The children had all been patients at the sole tertiary paediatric hospital in Western Australia, with a catchment area spanning 2.5 million square kilometres. Ethics approval was obtained, and informed consent from all the participants and their parents was collected. The first 13 children who required surgery for their burn from the recruitment start date were invited to participate. One parent of a child declined the invitation as he felt his child was too busy with school work. Total Burn Surface Area and life threatening injury was gathered from the patient's medical chart and length of stay and etiology of burn were not recorded for this study.

The interview guide consisted of open-ended probing questions that explored the experiences, perceptions, thoughts and feelings of participants in relation to their experience of a burn [7]. The main question of the interview was "can you share with me your experience of the burn?" The researcher then used prompts and probes to encourage the participant to tell their story, with the participant guiding the direction of the interview rather than the researcher, as is consistent with phenomenology methodology [9]. Open-

ended questions were asked about the accident, admission to hospital, surgery and recovery. The children's developmental age was considered when asking questions, with avoidance of closed questioning [9]. A pilot interview was conducted with a 14-year-old boy to ensure the questions and interview technique elicited information to meet the aim of the study [7].

Unstructured, face-to-face interviews were conducted with the children six months after the burn injury, at the participants' homes, allowing them to feel comfortable and secure in their environment and promoting confidence in disclosing their opinions and experiences [7]. Parents were present in the homes of children whilst the interviews were conducted, however parents were not in the rooms in which the children were interviewed, ensuring confidentiality was maintained. The time point was chosen as the most appropriate time point as it allowed children time to reflect, adjust, process and articulate their journey. Children aged 8-15 years were invited to participate as developmentally they have the skills required to accurately reflect on their experience as well as articulate their experiences verbally [10].

Rapport was established with the children prior to commencing the interview through conversation, play and drawing. The researcher travelled to the participants' homes, including travelling to rural and remote areas, to ensure a sample representative of the clinical population. The interviews lasted a minimum of 30 minutes in length and were digitally recorded. During the interviews, the researcher used a journal to record all non-verbal cues from participants and environmental factors of importance, as well as to reflect on the interview process [7]. Once redundancy in descriptions was reached, recruitment ceased [7].

3.2.3 Data Analysis

All interviews were transcribed *verbatim* and de-identified. Pseudonyms were created to protect participants' anonymity. The first author who has a clinical background in burns undertook the analysis. Data analysis was assisted by the use of QSR International's NVivo 9 qualitative data analysis software [11] and followed Colaizzi's method of qualitative data analysis [12] (see Table 3.1). This method allowed the researcher to reflect on and interpret emerging themes [12].

Table 3.1: Colaizzi's (1978) Data Analysis Framework Procedure [12]

- Step 1. Reading transcripts to acquire a sense of each transcript
- Step 2. Extracting significant statements from transcripts
- Step 3. Formulation of meanings
- Step 4. Organising formulated meanings into themes
- Step 5. Exhaustively describing the investigated phenomenon
- Step 6. Identification of the fundamental structure of the phenomenon
- Step 7. Validating the process by returning findings to participants.

An expert in the field of qualitative research reviewed the transcripts and utilised the same analysis method to ensure the credibility of the findings. Bracketing was used by the researcher to put aside previous knowledge and beliefs about the researched phenomenon [7]. The trustworthiness of this study was enhanced by an audit trail, member checks with participants and reflective journaling to record field notes and developing perceptions, questions and reflections on the progress of the study. Peer debriefing with the co-authors to discuss growing insights of the phenomenon also occurred [13].

3.3 Findings

3.3.1 Participant Characteristics

Twelve children (six male and six female) aged eight to 15 years old who required surgery for a burn injury were interviewed in this study. All interviews were conducted within the two weeks that would mark six months after the occurred. Total burn surface area estimates for the injuries ranged from one per cent to 20 per cent. None of the burns sustained by the children was described as life threatening.

All children identified themselves as Australian and two children were Aboriginal. Five children lived in rural and remote areas of Western Australia, including two children who lived in a remote Aboriginal community.

Analysis of the interview transcripts revealed that trauma was central to the burn experience and comprised two phases: the burn trauma and the recovery trauma (see Figure 3.1). Six themes emerged as a result of this experience: ongoing recurrent trauma; returning to normal activities; behavioural changes; scarring—the permanent reminder; family functioning and adaptation. All direct quotes are presented in italics and pseudonyms are used.

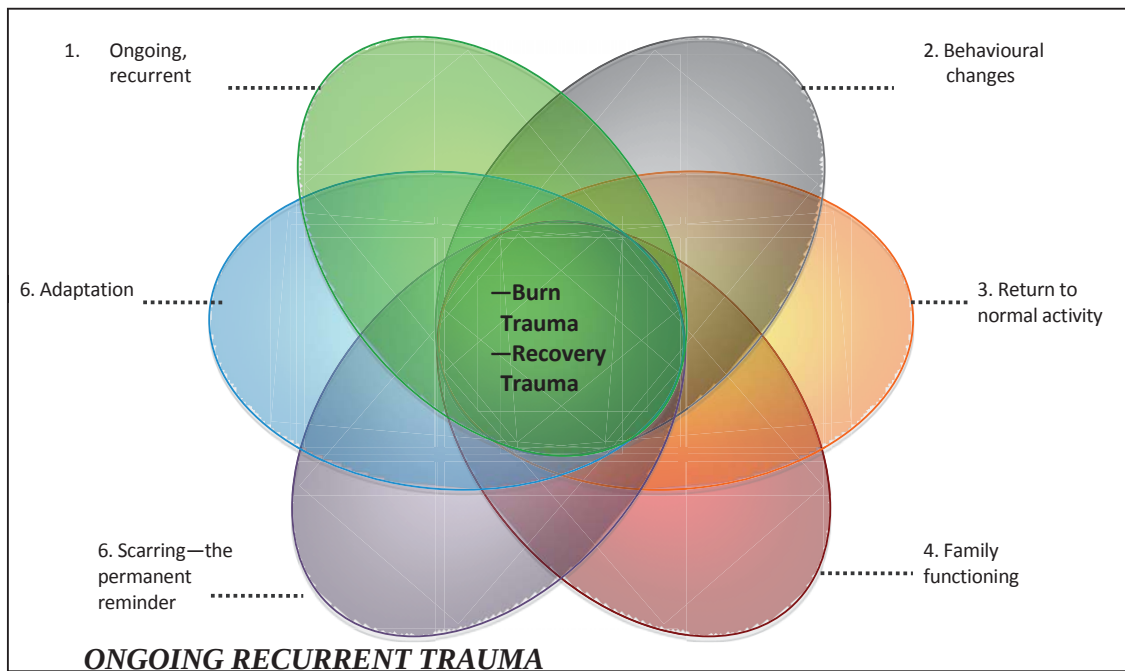


Figure 3.1: Identified Themes

This theme consists of both the initial trauma of sustaining the burn and the ongoing paediatric medical trauma that resulted from the burn treatment. All the children required one surgical procedure and dressing changes varied from a minimum of four to a maximum of 28.

3.3.2 The Initial Trauma: Sustaining the Burn

All children described feeling ‘scared’, ‘worried’ and ‘afraid’ at the time of the accident. Children feared they would ‘die’ or ‘lose a limb’. The majority of children relied on their parents to administer the correct first aid and support them emotionally, with many

children saying they were in ‘shock’ and they ‘let their parents do it all’. A few children in the sample were not in the vicinity of an adult when they sustained their burn and were dependent on siblings or friends to provide support at this time. These children described feeling ‘like [they] *didn’t know what to do*’.

John, a 15-year-old boy, described in detail his accident experience while cleaning his motorbike with a friend:

I was cleaning my motorbike with petrol ... and I completely forgot I had petrol on my hands, so I lit the match and my hands just went up in flames. I ran in and out of the shed a couple of times, patting my hands on my shirt, trying to pat them out and then my shirt caught on fire. I had burns down the whole right side of my back. I was thinking, this isn’t working, so I held my hands between my legs, then my legs started hurting [because they too caught fire] so I was like, great. I ran out of the shed and my mate had petrol on his hands so he couldn’t do anything. He said, ‘Stop, drop and roll’, so I tried that and it didn’t work. I managed to put the fire out on my back but my hands were still on fire, so I just thought, ‘Nup, this is it’. I just had to smother my hands in the dirt, it was full of old oil, grit and metal, but I knew I had to do it. The closest water was too far for me to go while on fire.

It was really scary. I was thinking of other burns patients that I have seen on the news that have lost their arms and legs and I was thinking, I don’t like the idea of body parts coming off or anything. I was just imagining the worst, like, I would end up with little stumps or something. I was concerned about losing a body part.

3.3.3 Ongoing Paediatric Medical Trauma

After the initial trauma of the burn, the children experienced ongoing and recurrent trauma. Medical events causing further trauma included surgery and dressing changes. For most children, this trauma continued for weeks and in some cases, months after the initial burn.

3.3.3.1 Surgery

Going into theatre was described by children as very ‘scary’ and caused them to ‘worry a lot’. The children ‘cried, because [they were] *really scared*’ and were concerned about ‘*what was going to happen*’ in theatre. Fear was described by the children as resulting from not knowing ‘*what the [surgeons] were going to do*’ or, ‘*how long [they were] going to be recovering for*’. Children described not understanding the medical procedures they were undergoing. This increased feelings of anxiety with some children misinterpreting the procedure or ruminating on inaccurate thoughts such as, ‘*I was scared they would take a big chunk of my leg off*’. Children were more concerned about their donor site than the burn site. Many of the children misunderstood the grafting process and were concerned how their donor site would look with a ‘*bit missing*’.

Despite assurances from health professionals that they would wake up once their surgery was complete, several children still feared they ‘*would never wake up again*’. In particular, both the Aboriginal children involved in this study were very fearful in this regard. As described by a 12-year-old girl with an arm burn, ‘*I didn’t want to do it. Yeah, I didn’t really like being knocked out. I was thinking, I’m not going to get back up, I’m never going to wake back up again*’.

The importance of family in providing support and normalising the children’s experience of surgery was described by several children:

Yeah, but once I spoke to my uncle, because my uncle’s had lots of accidents, once he talked to me it was sort of all right. He said you don’t feel any pain, and that made me feel better (Joshua, 12-year-old boy).

In contrast, Amy, an 11-year-old girl, described how she was certain she would wake up during surgery as a result of the pain. Although this was a real fear for her, she did not discuss this with the health professionals:

I was really, really scared because, I really thought I would wake up during the surgery ... When I went to sleep [under general aesthetic] I thought the pain would be so bad I would wake up. The doctors said I would be asleep the whole time, but I thought I was definitely going to wake up ... No, I didn’t talk about it with anyone; maybe a little bit with my mum.

There appeared to be an association between surgery, sleep disturbance and the onset of disturbing nightmares. Surgery provoked a sense of increased arousal in children with many describing disturbances in sleep and nightmares. Some children experienced nightmares every night during their time as an inpatient. Gemma, a 12-year-old girl, described a vivid recurrent dream she experienced repeatedly after surgery:

Yeah, I had a dream that my Dad had a knife and peeled all my skin off ... yeah, it was a really weird dream; it freaked me out.

3.3.3.2 Dressing Changes

While the children in this study described experiencing relief to have woken from surgery and in overcoming this challenge, they also reflected on understanding that they would have to endure further medical procedures. They knew that surgery was *'really only the beginning'*. The children commonly described dressing changes as the most traumatising and frightening part of their experience of having a burn. Dressing changes were traumatic both because of the pain but also because they had to witness invasive medical procedures. Children described it as, *'the most painful thing [they] had ever done'*, and that they *'didn't know the human body could experience so much pain'*.

Some children described experiencing physiological symptoms of psychological stress, such as having difficulty breathing and feeling faint. Three children described their experience:

The scariest part was when they had to cut off the dead puffs of skin (George, eight-year-old boy).

I had my hands up and people were either side with tweezers and my hands were completely red, with no skin whatsoever on them (John, 15-year-old boy).

You know, [taking off the dressing] would rip all the skin and I started crying and they just tore it all off. And I didn't like it for the first few maybe four changes, because all the stuff would stick and it would really hurt pulling it all off (Sally, ten-year-old girl).

Many children found the first dressing change confronting. Children described being ‘shocked’ at the sight of their burn; *‘I felt so silent, it looked really ugly, I hadn’t expected [the burns] to be like that’*. Seeing their body in this context forced children to confront thoughts of ‘why me?’ As one boy described:

I actually thought it was never going to be the same again. I guess it’s not really going to be the same again. It was just different, and I wondered why it was me, like, why not some other kid, or why did it have to be me? (Jim, 13-year-old boy).

Some children described ‘*thinking the worst*’ when they saw their skin. Others described using positive affirmations to help them through this stage, focussing on the fact that they ‘*hadn’t lost any limbs*’. A few children found themselves being concerned about their future when they saw their wounds and felt scared about the ‘*unknown*’:

I was feeling scared because of what other people will think of me and, like, scared of what’s going to happen to them after they’re fully healed, because if there’s going to be scars or not (Mary, 13-year-old girl).

I was just like, ‘Wow, this is what’s happened. This is going to have a huge impact on my life’ (Donna, 13-year-old girl).

The majority of children reported experiencing anticipatory anxiety prior to dressing changes. Children described feeling ‘worried’, ‘nervous’ and ‘scared’ prior to the procedure because they ‘*didn’t know what was going to happen*’ and they were ‘*scared that it would be painful*’. Two children described this experience:

Probably, when I first had to do my dressing change, that was bad, because I had to sit in the bath, and even if I got water on myself through the bandages I’d be scared because, like, in case it stung, and if they felt like checking underneath and like water usually stings them, and so I was scared of that. But then, they managed to put cling film on, and yeah, it was better than I expected (Donna, 13-year-old girl).

It was pretty scary, going back every day. Just knowing they’re going to touch it. I hated the car ride to the hospital because I knew what was going to happen (Jim, 13-year-old boy).

An older child, Mary (aged 14), described how she found the distress she experienced with dressing changes embarrassing:

Like having to go through the pain and everyone's watching, so it's embarrassing that everyone else sees how much pain you're in.

3.3.4 Return to Normal Activities

An added burden of the injury was the loss of independence children felt as a result of the burn. Children who required assistance from parents or nurses to perform self-care tasks such as toileting, bathing and dressing described feeling 'incapable' and 'disabled'. This produced feelings of 'frustration' and 'annoyance':

Yeah, because normally you can do stuff on your own but when accidents happen like this, you're just left and everyone else is doing everything for you, which is frustrating (Mary, 13-year-old girl).

Children who were less distracted on the ward described having a lot of time to think. Lack of ward distraction resulted in children ruminating on thoughts of a catastrophic nature, such as worst-case scenarios, questioning if they would 'ever walk again', or if they would be able to 'draw like I used to'. John, a 14-year-old boy, described his thoughts during this time:

You spend that much time [in hospital] doing nothing, just lying in bed, looking at the roof, so I thought about everything you can imagine ... my biggest concern was would I be able to use my hands, and would I be able to run?

For many of the children, sport was a measure of functionality. As their wound was healing, children were upset and disappointed they could no longer participate in their favourite sport. Some children described missing out on playing in tournaments they had trained all year for, while others felt 'annoyed' and 'frustrated' sitting on the sidelines watching their teammates. Sport provided children with a sense of hope and was a motivating goal, encouraging them to persist with rehabilitative exercises. A few children described not being able to resist playing sport although they had been informed by medical staff that it was unsafe to do so:

When I went to school camp, even though I wasn't supposed to, I did run again. I couldn't help it, everyone else was doing stuff and I was just like, 'I want to do that too' (Mary, 13-year-old girl).

In contrast, some children described hyper-vigilant behaviours of being overly concerned and protective of their scar. Despite receiving permission from medical staff, they preferred not to participate in sports, *'in case their scar became infected'*, or *'something bad happened to it'*.

All of the children described being *'happy'* to return to school. The children missed school, mainly because they *'missed their friends'*. Some children were *'concerned'* about needing to *'catch up'* on schoolwork and worried they would *'fall behind'*. Returning to school in pressure garments prompted many questions from fellow students, which most children described being happy to answer. However, some children found it *'annoying, always answering everyone's questions'*, while others *'avoided'* answering questions because it made them feel *'uncomfortable'* and *'embarrassed'*.

In one child's case, she described re-experiencing the event every time she was asked how it happened: *'it felt like I was back at the time I got burnt, it brought me back to that time'*. Three children described their experience of returning to school:

Some kids are mean but you just have to not focus on that, because they're just people that want attention. So, focus on the people that aren't saying that because that's who your true friends are (Mary, 13-year-old girl).

Like, all of the girls were really shocked when they saw them. No one expected my burns to be that bad (Donna, 13-year-old girl).

I felt sort of like the centre of attention, but I didn't want to be it. I sort of wanted to get home, really; I didn't want anybody really looking at me (Amy, 11-year-old girl).

3.3.5 Family Functioning

All the children described the importance of family. During their inpatient stay, the children described feeling 'lonely', 'sad', 'bored' and 'scared' during the times when their parents or siblings were not in the hospital. Children who lived in rural towns described missing their families and feeling lonely, as Lucy, a ten-year-old girl from a remote Aboriginal community described, *'the hardest part for me was being away from my family, I really missed them'*. Other children described reuniting with their siblings at home as the best part of being discharged. All the children were grateful for the support their parents and siblings had given them. Mary, a 13-year-old girl described:

Yeah, Mum helped a lot. I wouldn't have done anything without Mum. I'd probably still be in the hospital if I didn't bring her.

Many of the children showed maturity by reassuring and comforting their parents when they saw them upset, as Georgia, a ten-year-old girl explained:

Well, I told him to stop like crying and being upset. I said, it's going to be okay, Dad.

Two girls described how their parents felt guilty over the accident and described how they comforted their parents by reassuring them it was not their fault:

I kept telling Dad it wasn't his fault and not to be upset. Because he was saying it was his fault that I was in there (Amy, 11 years old).

A few children described their own guilt and how they felt they *'had stressed their mothers out'* by sustaining the burn. Children also described feeling guilty because their mothers *'don't have time to be massaging [my] scar'*. Amy described how the responsibility of her scar management caused arguments among her sisters and mother:

Because now I think that my Mum's stressed because she has to help me and well, if my Mum, like, say, if we went to tennis camp and my mum wasn't there, my sisters had to help and sometimes they would not do as good a job as my Mum did, and then we argue about it.

Children reported that their parents had become more overprotective of them. They described frustration at being told *'what they should and shouldn't do all the time'*. As described by Amy above, the majority of parents took responsibility for their child's scar

management, although their children were capable of independently undertaking this task. The children felt that their parents were concerned, both about damage to the scar, as well as the possibility they might have another accident:

[Mum] says things like *'We can't go to the beach because we'll get sand on our graft and it could get infected'* (Jim, 13 years old).

Yeah, because when we were coming here, we [she and her sisters] had to cross the road and my Mum was really worried and, like, we knew how to cross the road but [my Mum] was still worried (Amy, 11 years old).

3.3.6 Scarring-The Permanent Reminder

For some children, it *'bothered'* them to look at their scars, because *'it doesn't look like other skin'* and it, *'feels bumpy and yuck, and like seeing the inside of your skin'*. A few children avoided touching their scar and had to *'force'* themselves to massage it. Children described showing their scar to only friends they could *'trust'*, and some children described the comfort they found in wearing pressure garments because this prevented people from viewing their scars. As Mary, a 13-year-old girl explained:

I was also relieved that people can't judge me, because when you walk past people they can't judge you because, if I'm wearing long pants over my pressure garment, they don't know that this is going on underneath. But, if it's summer and I'm not wearing pants, they can easily judge you and be like, 'I don't want to be friends with her, she's a lot of trouble', because that's what happens.

Children were *'happy'* to see their scars improving over time and were looking forward to seeing further improvements. However, many children were unrealistic about their expectations, stating, *'my skin will look like normal skin in another six months'* or, *'I know it [the scar] will go away'*. Children appeared to be blurring feelings of hope with reality. Photos provided children the opportunity to reflect on how they had healed and were identified as a therapeutic process. Children described feeling *'relieved'* to know they have improved over six months:

I'm actually happy that it's healing because that just makes me feel like the sooner it heals, the sooner I'll be able to get on with my life, like, I'll be able to

walk around without my leggings on and all that. I'll be able to go in the sunlight again (Mary, 13-year-old girl).

I feel happy and proud because Mum took pictures of how it's going and sometimes I go, like, wow, did it really look like that, and so I'm relieved that it's getting better and it's going smoothly (Amy, 11-year-old girl).

Children described feeling 'disappointed' when informed that they needed to wear pressure garments. They were 'worried' about what they would look like and concerned that they 'would have to stay inside all day' because the garments would prevent them from doing activities they enjoyed. Two boys describe their experience of wearing pressure garments:

No, I don't like it. It looks like a stocking. I just hated how you walk around the shops and people look at it and are like, 'What is on your leg?' (Jim, 13-year-old boy).

When I first got my sock, I didn't really want it, you know, like, I wanted it to be off, I wanted to be normal, I didn't want to have a burn (Todd, ten-year-old boy).

3.3.7 Behavioural Changes

It is inevitable that children experience behavioural and emotional changes as a result of a traumatic injury such as a burn. These changes were described by the children and included symptoms of ASD, with children experiencing avoidance and hyper-vigilance with increased arousal. Although re-experiencing symptoms are a prominent symptom cluster in acute stress disorder, children in this study did not volunteer experiences consistent with these symptoms.

3.3.7.1 Avoidance

All children, with the exception of two, reported never using the object that caused their injury again. Some children were able to say, 'when I'm older I will use it again', where other children stated, '[they would] never use it again'. For one boy, looking at a

motorbike made him 'teary' and another girl described how watching boiling water brought back memories of her burn from a hot-water bottle, and how it made her feel 'funny':

Really, since that moment, I've never cooked a marshmallow over a fire ever again. I stay at least two metres away from the fire, like, I'm really scared of bonfires now. Sometimes I don't even go down when my friends are down there (Todd, ten-year-old boy).

I'm never waxing with a hot pot of wax again (Mary, 13-year-old girl).

If I need to do jobs, I don't go on it [ride on lawnmower]. But when I just walk around it I'm fine (Bobby, eight-year-old boy).

3.3.7.2 Hyper-vigilance

Children described hyper-vigilant behaviours such as, 'I worry I will hurt myself again' and, 'I stick around [my] Mum and Dad a lot more'. All children reported being more 'safety cautious', 'wary' and 'careful' since their burn. Children described how they now 'weigh up all the risks involved' before doing activities, and were always thinking about 'what could accidentally happen'. As one child explains:

I'd like give everything a second thought and I'd contemplate whether or not I should be doing it (Donna, 13-year-old girl).

3.3.7.3 Internalising Symptoms

Increased arousal was commonly described by children. A ten-year-old girl, Georgia, described how she felt anxious a great deal of the time, which often manifested in daily stomach pains. Some children ruminated on negative thoughts of 'why me?' and, as some children described:

Maybe once a week I think about why did this happen and then I wish it didn't happen. It's frustrating (John, 14-year-old boy).

But, when you stop moving and doing stuff, that's when you start thinking ... sometimes it still scares the hell out of me, thinking about it (Jim, 13-year-old boy).

Just night-time, I start thinking about stuff, because I'm going to bed and I've got nothing else to think about. But, it is almost always night-time, and then I can't go to sleep, so I keep on thinking (Todd, ten-year-old boy).

3.3.8 Adaption

Children described how the event changed them as a person. Surprisingly, some children were able to positively reframe their experience describing that they were 'stronger' because of the experience and had more 'confidence'. Other adolescents reflected, 'small things don't annoy me anymore' and, 'I no longer let the bad things get too important'.

Two children described how their experience had motivated them to help other children in the future and they would like to do this by focussing their career path on becoming a health professional. Children also showed resilience by viewing their burn as 'something that happened and I really just have to live with':

Yeah, I'm definitely stronger. Because once you've gone through something as un-ordinary as this, it just changes you, because you become a whole different person by the time you're let out. It's all the experiences you get. It's not like everyone gets these experiences so everything happens for a reason, so I think I was supposed to go through this to make myself confident and make myself stronger (Mary, 13-year-old girl).

Yeah, because it sort of changed everything because now I'm thinking that I should maybe be a burn doctor. I want to help other people. Before, I wanted to be a vet, but after the experience I've had, now I want to be a burn doctor (Amy, ten-year-old girl).

3.4 Discussion

This study identified two phases of trauma central to the burn experience. Children described the first phase (the burn trauma) as the event of sustaining the burn and seeking medical assistance, whereas the second phase (the recovery trauma), involved medical procedures. This research identified that children experience ongoing trauma in addition to the initial trauma of sustaining the burn, resulting in a cumulative trauma experience. These experiences led to behavioural and emotional changes in children and within family functioning. Six themes were identified in data describing the child's experience: ongoing recurrent trauma; return to normal activities; behavioural changes; scarring-the permanent reminder; family functioning; and adaptation.

Paediatric medical traumatic stress refers to the psychological and physical responses experienced by children and their families as a result of encountering pain, injury, serious illness, medical procedures and invasive and frightening treatment experiences [14]. The model of paediatric medical traumatic stress was developed to conceptualise the experiences of children and families within medical settings. The model encapsulates paediatric medical trauma as a continuous process accounting for paediatric medical traumatic stress at various phases within treatment and illness progression. The patient and family's experience of trauma is described as moving through three phases: Phase I, the occurrence of the potentially traumatic event; Phase II, early (acute), ongoing and evolving traumatic stress responses; and Phase III, longer-term traumatic stress responses [14].

Data from this study did not validate the three phases of the model of paediatric traumatic stress. Phenomenology reveals and illuminates general assumptions about an experience, allowing a deeper perceptive and understanding of the essence of the lived experience [7]. Using this methodology, child participants did not describe their experience as a continuum of phases, but as an individual journey. Although the model of paediatric medical traumatic stress is descriptive in terms of a child or family moving between the phases in a non-linear pattern, the current findings indicate that recurrent trauma frequently occurs during the acute phase for some children, suggesting recurrent movement between Phases I and II. Investigating the child's lived experience using

phenomenology enabled a greater understanding of what living with a burn is like from the perspective of the child, a phenomenon that, until now, has not been documented. The data reveals that behavioural and emotional changes in children and within family functioning are present. The current research demonstrates that paediatric medical trauma can affect all aspects of child wellbeing.

Dressing changes and surgical procedures are imperative to the physical outcome of the burn and are an essential part of burn care. Children in this study described not knowing what was going to occur during surgery or dressing changes. This evoked fear in the children, who also described ruminating on false assumptions, increasing emotional distress. Preparatory information about medical procedures has been observed to improve child behaviour and reduce distress [15, 16].

A critical review of the literature on procedural preparation provides evidence-based recommendations for providing information on medical procedures to children [17]. Recommendations include content of information, format of information and timing of information [17]. These factors are important to consider because children who are highly aroused may have difficulties processing and remembering information. Research on the role of information in preparing children for burn-related medical procedures is scarce and warrants further investigation.

The children in this study described experiencing anticipatory anxiety, increased arousal and severe pain during dressing changes. It has been clearly documented that burn pain is often underestimated and undertreated [18]. Appropriate pain management is fundamental to minimising the onset of secondary complications such as anxiety and PTSD in children with burns. Research has shown a significant correlation between higher doses of morphine and the reduction of PTSD symptoms in children six months after a burn [19].

In addition to pharmacological methods of pain control, non-pharmacological methods also play an important role. Non-pharmacological methods include cognitive techniques (distraction techniques), behavioural techniques (conditioning/relaxation techniques) and learning techniques (preparation for procedures and education). Strategies such as distraction devices have been shown to decrease levels of pain during dressing changes [20, 21] and behavioural techniques such as breathing and relaxation have been associated

with lower anxiety [22, 23]. Vigilant assessment of pain and implementation of pharmacological and non-pharmacological methods of pain management are required to minimise subsequent problems associated with pain during invasive and frightening medical procedures.

Although the majority of children described being happy upon their return to school, a small subset reported negative experiences. Children in this study described difficulties discussing their burn at school, being the centre of attention and dealing with malicious children. Community distress was also described by children, as they explained how their friends were shocked to see the extent of damage the accident had caused. Hospitals can work with schools to prepare and educate staff and students to enhance the transition from hospital to school for children with burns.

A recent critical review of the psychological consequences of paediatric burns highlights the need for further research into bullying [2]. Currently, the only quantitative study to investigate bullying and paediatric burn patients reported that 61 per cent (n=250) of children were bullied about their scars at school and the finding that just under half of those bullied did not inform an adult is concerning [24]. Headaches and stomach-aches due to bullying were reported by 25 per cent of children [24]. This study demonstrates that bullying affects both mental and physical wellbeing in children, highlighting that effective evidence-based interventions are required.

The current findings show that some children are unhappy with the appearance of their scar, struggle to touch their skin and avoid showing others their scar. Body image is a concept developed by sensory and social experiences [25]. Social experiences include how people in society react to one's body, which can consequently shape how an individual responds to their body [25]. Research has found that children with burns who have negative body image have lower quality of life, experience negative moods and feel stigmatised and uncomfortable in social scenarios [26]. To date, burn camps are the only published intervention to show improvements in body image for children after a burn accident, but research on this intervention is limited [27]. Development of other effective interventions is clearly needed.

Of interest in this study is the discrepancy reported between hope and the reality of the scar outcome. Many children described how they believed their scar would disappear. This discrepancy raises questions in relation to how health professionals can prepare children for the future: to provide hope, but also maintain realistic expectations about scar outcomes. This area requires further clinical and research attention, as it is unclear from the data if children are misinterpreting messages during rehabilitation sessions with medical staff.

Children in the present study reported behavioural and emotional changes such as avoidance, hyper-vigilance, increased arousal and internalising behaviours. Quantitative research reports symptoms of PTSD decrease over time in children [28]. However, the six-month period described in this study appears to be a critical time during which children require psychosocial intervention. In addition to their behavioural changes, children in this study were insightful into changes within family functioning. Children described an increased dependency on parents and felt isolated when parents were absent. Some children identified feelings of guilt about the burden their injuries had caused their families, thus adding to their emotional burden. Children also reported providing emotional support for their parents and noticed their parents had become overprotective. These concepts of child guilt and child parentification are not well documented in burns literature and require further investigation. However, family functioning has consistently been found to affect child outcomes [2], and the quality of family and social support has been shown to play a critical role in the adaptation process [29]. For this reason, it is important health professionals encourage and facilitate family-centred strategies for care and assess family functioning in both the inpatient and outpatient phases.

Post-traumatic growth describes positive life changes, including improved personal strength, appreciation of life and spiritual change [30]. Little is known about how children grow from the experience of sustaining a burn. This research demonstrates that some children experienced post-traumatic growth as a result of sustaining their burn. Children described processing the event to reframe their experience into a positive experience. In an older sample of nine young adults (mean age, 19) in South Africa, experiences of resilience were described, where participants also described positively reframing their experience and positively transforming themselves [6]. Gaining a greater understanding

of post-traumatic growth in children will lead to the development of effective interventions aimed at promoting recovery and resilience in children.

3.4.1 Limitations

Although findings from this study were replicated among participants and correlate with findings in other quantitative studies, these findings cannot be generalised to all paediatric burn survivors. This research used one time point for data collection but multiple interviews at three time points, including after the event, the inpatient phase and the outpatient phase would be of benefit for future studies to gain an expanded understanding of each stage. Future research should investigate the prevalence of the identified themes in quantitative studies. Quantitative investigation of changes within family functioning, behaviour adaptation and return to school is required.

One strength of this paper is that it provides a voice for the child's experience of sustaining a burn. Although this methodology poses challenges it has enabled the description of children's experiences from their perspective. Children within the age range selected (eight to 15 years) were adequately able to articulate and reflect upon their experiences. Parents and children both felt valued as a consumer and empowered to use their experiences to help other children with burn injuries. This methodology allows future research to be driven and guided by those individuals who have experienced the phenomenon first hand and provides a voice for burn survivors.

3.5 Conclusion

The qualitative methodology of this research provides a voice for the child's perspective of the burn experience. This research has clinical implications and findings that could be used to inform clinical care at all stages of the burn journey from the perspective of the child. These research conclusions may assist the development of comprehensive information and support management plans for children. This would complement and support the surgical and medical treatment plans, providing direction for a holistic service delivery and probable improved psychosocial outcomes in children with burns.

3.5.1 Conflict of Interest

No authors report a conflict of interest.

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Chapter 4: Paediatric Medical Trauma: The Impact on Parents of Burn Survivors

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The full, published paper is provided as Appendix A.

Foreword

The previous paper described the lived experience of children who sustained a burn injury. Children are embedded in the context of families and to provide family-centred care, it is important to consider their ecological framework. Parents are integral to the outcome of children and thus the psychological response of parents to the trauma of a burn injury is imperative. This paper aims to investigate the impact of exposure to paediatric trauma on parents of children with a burn and to identify risk factors and relationships between psychological distress and resilience.

4.1 Abstract

Introduction: To identify parents at risk of developing ongoing psychological distress after their child has sustained a burn, a greater understanding of paediatric medical trauma is required.

Aim: To investigate the impact of exposure to paediatric trauma on parents of children with a burn and to identify risk factors and relationships between psychological distress and resilience.

Methods: Sixty-three parents were recruited. Parents completed standardised assessments measuring symptoms of post-traumatic stress disorder (PTSD), depression, anxiety, stress and resilience within one week of the burn occurring. Statistical analysis included *t*-tests, Kruskal-Wallis one-way ANOVA (analysis of variance) and Spearman's rho.

Results: Parents experienced significantly more symptoms of PTSD ($p=.000$) than a comparative community population. Factors including having a daughter, witnessing the event, feeling helpless or having past traumatic experiences significantly influenced symptoms of psychological distress and resilience ($p=.05$).

Conclusion: Parents of burn survivors experience significant psychological distress with low levels of resilience. As part of standard routine care, health professionals should screen parents to identify those at greatest risk and provide effective evidence-based interventions aimed at improving resilience and reducing stress.

4.2 Introduction

Burn injuries are a serious global health threat to young children [1]. In Western Australia in 2008, 7,305 children aged 0–15 years were hospitalised for a burn [2]. Children under 15 years accounted for 31 per cent of all burn-related hospitalisations in Western Australia [2]. It is estimated that 250 per 10,000 children aged zero to four are hospitalised for a burn injury in Western Australia [2]. Improved surgical and medical interventions mean more children survive burn injuries [3] and the quality of physical scars is improving [4]. However, it is vital to address underlying emotional scars.

Paediatric medical traumatic stress refers to the psychological and physical responses experienced by children and their families as a result of encountering pain, injury, serious illness and invasive medical procedures [5]. Symptoms of PTSD are identified in children who experience a traumatic accident such as a burn [6–8] and limited studies have addressed the psychological impact on the parents of a child who sustains a burn. Parents need to help their child cope as an inpatient in hospital and often experience stress as they make complex treatment decisions while witnessing their child in pain, frequently in the context of self-recrimination and concern for their child's future. Once discharged, children are dependent on their parents for the correct after-care of their burn including extensive wound-care, pain management and attending hospital follow-up. If parents are experiencing significant levels of psychological distress, their daily functioning may be impaired [9].

The available research evidence investigating parental responses to burn injuries in children has shown that parents experience clinically significant symptoms of PTSD in the acute phase (one to four weeks post-burn) [10–12]. Reported rates of PTSD symptoms in this phase vary across studies, with rates reported between 18.8 per cent ($n=16$ mothers) [10] and 50 per cent ($n=182$ mothers) [12]. During the acute phase, it has also been reported that parents experience symptoms of anxiety and depression with rates of symptoms varying from 18.8 per cent ($n=16$) [10] to 69.9 per cent ($n=16$) [13].

To date, no studies have investigated resilience levels of parents of burn survivors or the relationships that exist between resilience and adverse psychological outcomes.

Resilience is the capacity to positively adapt and cope despite adversity [14], which has been described as an innate psychological immune capacity, and may be an underestimated concept that is missing in trauma literature [15, 16]. It has been suggested that to completely understand dysfunction as a result of trauma, a greater awareness of resilience is required [15]. Investigating the capacity of resilience in parents of children with burns is important to explain why some families survive the psychological effect of burns trauma. This understanding will be helpful in developing strategies to assist families in the future.

Previous research investigating the wellbeing of fathers is limited [12, 17], with the notable exception being a recent study that investigated acute stress reactions in 154 fathers one month or less after their child sustained a burn [12]. Findings from this research showed fathers reported less clinically significant acute stress reactions compared to a sample of 183 mothers [12]. This study enhances understanding of the experience of fathers, although more research is required to explore this area further.

Relevant epidemiological research in Australia has found that children of fathers who show signs of depression in the first year after birth have more than three times the rate of behavioural problems by the time they reach school, compared to children whose fathers do not have symptoms of depression [18]. Given that infants and toddlers represent the highest age group for burns admissions throughout the Western world [1, 2], developing an understanding of the mental health of their fathers is critical. Other research describes increased rates of developmental and mental health problems in children of fathers with even mild symptoms of mental illness [18, 19]. Documentation of mental health impairment in the fathers of burns survivors could lead to the development of effective therapeutic supports.

Previous studies of parental distress within a burns population have studied the period two months after the injury with few studies assessing parental distress within 48 hours to two weeks post-injury [10, 13, 20, 21]. Identification of precursors in the acute stage while children are inpatients may help to identify parents at greater risk of mental health issues once discharged into the community. Predictive factors known to influence psychological distress in parents of children with burns include being a mother [12], the younger age of the mother [13], lower emotional stability [13], poor family functioning [13] and family

conflict [20]. Varying evidence has been reported on the size of the burn as a predictive factor; some studies show that it does predict parental distress [12, 20], while others report no relationship between psychological distress and the size of the burn [13]. Identifying parents at greatest risk allows for the provision of immediate services, encouraging ongoing therapeutic engagement and benefiting the mental health of parents, which may optimise adherence to treatments for burns victims [22].

It has been identified that people from Aboriginal populations are more than twice as likely to sustain a burn, [3] have higher rates of pre-existing mental illnesses [23] and have high levels of life stressors [23]. Forty-one per cent of Aboriginal people in Western Australia live in remote or very remote areas [24] and connection with land is central to their wellbeing [23]. Aboriginal children who sustain a burn in a rural or remote community are flown with one parent to the children's hospital in the city. Many of these children have never been out of their community, on a plane or in a hospital. In addition to the physical context of the burn, being away from family and land can add to the stress experienced as an inpatient. To our knowledge, no research has investigated the experiences of Aboriginal families in relation to burn injuries. This highlights that culture should be considered in future psychosocial research. In Australia, a greater appreciation of the needs and experiences of Aboriginal parents is vital.

It has been suggested that extensive psychological research is required in the area of traumatic stress to develop effective interventions for broader populations, as well as documenting prevalence rates [25]. Improved understanding of the relationships between resilience and adverse psychological symptoms and a consideration of the differences between the gender of parents and cultural effects may assist in the understanding and management of paediatric medical traumatic stress.

This study poses three hypotheses: (a) the psychological profiles of parents exposed to paediatric medical trauma were less optimal than population norms; (b) pre-existing factors were associated with psychological responses in parents; and (c) relationships exist between symptoms of psychological distress and resilience. These hypotheses were investigated within the total population sample and sub-populations of gender and Aboriginality.

4.3 Method

4.3.1 Participants and Procedure

Princess Margaret Hospital is the sole tertiary paediatric hospital in Western Australia. Parents of children admitted to Princess Margaret Hospital for a burn injury requiring at least one overnight stay were invited to participate in the study. One researcher was responsible for data collection and all new burn admissions between daytime working hours on Monday through to Friday were invited to participate. Participation was voluntary and of those parents asked to participate, 90 per cent agreed. Only three parents declined, as they were ‘not interested’ and six parents failed to complete the questionnaires.

Both mothers and fathers were invited to participate where possible, although in most cases, only one parent completed the assessments. Data collection occurred from February 2011 to January 2012 and parents self-completed assessments within one week of the burn occurring. Ethics approval was received from the Ethics Committee of Princess Margaret Hospital (Project 1855) and Edith Cowan University. Parents completed an assessment battery of screening tools and additional information including gender, age, ethnicity, income, employment, marital status and whether a mental illness had ever been diagnosed. Data collected on the child’s burn included mechanism of injury, size, location and depth of burn, and if surgery was required.

4.3.2 Measures

Four measurement tools were selected to measure the various facets of the potential impact of paediatric medical trauma. All are screening tools and cannot provide a definitive diagnosis.

4.3.2.1 Resilience

The Connor-Davidson Resilience Scale (CD-RISC) consists of 25 items scored on a five-point scale, with higher scores indicating greater resilience levels [26]. Scores range from 0–100. The CD-RISC has sound psychometric properties, demonstrating good internal

consistency ($\alpha=.89$) and test re-test reliability ($r=.87$) [26]. As no data has been collected on the Australian general population, comparisons were made with normative data from the US general population ($N=577$) [26].

4.3.2.2 Post-Traumatic Stress Disorder

The Impact of Events Scale—Revised (IES-R) [27] is the most widely used measure of PTSD symptoms in adults [28]. The scale consists of 22 items that represent all DSM-IV symptom clusters for PTSD. Good reliability has been reported with Cronbach's alphas ranging from .85, .88, .90 and .95 for each symptom cluster [29]. Higher scores indicate greater distress with scores ranging between 0–12. As no data has been collected on the Australian general population, comparisons were made with 138 adults in the US general population who had no trauma history [30]. To enable comparison between the two populations, scoring according to the earlier version of the assessment (Impact of Event Scale) was used. Scoring for the subscale hyperarousal was according to the IES-R.

4.3.2.3 Depression, Anxiety and Stress

The Depression, Anxiety and Stress Scale (DASS-21) [31] strongly correlates with other measures of depression and anxiety, indicating good convergent validity. Good reliability has been reported with internal consistency ranging from $\alpha=.82$ for anxiety, $\alpha=.90$ for stress and $\alpha=.93$ for the total scale [32, 33]. Comparisons were made with normative data from an Australian population sample of 497 [34]. Higher scores indicate greater distress with scores ranging between 0–126.

4.3.2.4 Predictive Factors

The Screening Tool for Early Predictors of PTSD [35] contains four questions for parents used to identify those parents at risk of developing symptoms of PTSD. Scores range from 0–4 with higher scores indicating greater risk. The sensitivity in predicting PTSD in parents was 0.96 with an odds ratio of 26.6 (95 per cent CI, 3.5–202.1) [35].

4.3.3 Data Analysis

Visual inspection of histograms and Shapiro-Wilk and Kolmogorov-Smirnov tests confirmed that none of the outcome variables (except resilience) were normally distributed. For this reason, the data is described with non-parametric statistics. The study was restricted to using parametric statistics (*t*-tests) when comparing data to previously collected control data due to the availability of published results, as most articles do not report median values. Cohen's *d* was reported for the *t*-tests to indicate the magnitude of the difference between sample mean and population mean. Kruskal-Wallis one-way ANOVA (analysis of variance) was performed to identify statistically significant differences between outcome variables in groups defined by pre-existing factors such as age and gender. Spearman's rho was used to estimate correlations between outcome variables. A *p* value < 0.05 was considered statistically significant. All analyses were performed in SPSS 19.

4.4 Results

Table 4.1 describes the sample demographics. The sample consisted of 63 parents, 46 mothers and 17 fathers of which five were mother/father dyads. Of the sample, just over half (52.4 per cent) were aged between 35 and 44 years and seven parents had a previously diagnosed mental illness.

Table 4.1: Sample Demographics of Parents

Sample Descriptor	<i>n</i>	%
Gender		
Female	46	73
Male	17	27
Aboriginal	12	19
Age		
Less than 25	2	3.2
25–34	20	31.7
35–44	33	52.4
45–54	7	11.1
Married	41	65.1
Living with partner/ <i>de facto</i>	10	15.9
Widowed	1	1.6
Divorced or separated	9	14.3
Never married	2	3.2
Employment status		
Full-time employment	24	38.1
Part-time employment	12	19.0
Not employed	27	42.9
Income		
\$41,600 or more	44	70.9
\$41,600 or less	9	14.5
Not reported	9	14.5
Diagnosed mental illness	7	11.1
Home		
Metro	25	39.7
Regional	14	22.2
Remote	20	31.7
Not reported	4	6.3

Table 4.2 describes the demographics of the children and the characteristics of the injury. The mean total burn surface area was 4.12 per cent, $SD=4.05$. Arm burns were the most common burn (14 children), followed by chest (ten children) and foot burns (ten children). The majority of children sustained a scald (48.8 per cent) or a contact burn (32.7 per cent).

Table 4.2: Sample Description of Children

Sample descriptor	<i>n</i>	%
Age		
8 months–2 years	20	34.5
3–8 years	20	34.5
10–16 years	18	31.0
Gender		
Males	37	63.8
Females	21	36.2
Total burn surface area		
0.5 to 2%	23	41.1
2.5–5%	21	37.5
6–15%	12	21.4
Depth of burn		
Superficial	9	15.5
Partial thickness	11	19.0
Full thickness	38	65.5
Surgery		
Yes	47	81.0
No	11	19.0

Parents experienced significantly more symptoms of PTSD than the US general population ($p=0.00$, $d=0.77$) with significantly more symptoms of intrusion ($p=0.00$, $d=1.03$) and avoidance ($p=0.01$, $d=0.55$) (see Table 4.3). Thirteen parents (21.3 per cent) had total scores of 33 or above, meeting the threshold for clinical concern and diagnostic accuracy [36].

Table 4.3: Outcomes Compared to Population Reference Groups

Variable	Sample <i>M(SD)</i>	Reference group <i>M(SD)</i>	Mean difference [CI]	<i>d</i>	<i>p</i>
IES total	14.31 (11.54)	8.10 (12.3) ^b	6.21 [3.26–9.17]	0.77	0.000
Intrusion	7.93 (7.04)	3.9 (6.2) ^b	4.03 [2.23–5.84]	1.03	0.000
Avoidance	6.38 (5.45)	4.2 (6.8) ^b	2.32 [0.92–3.71]	0.55	0.001
IES-R					
Hyperarousal	0.87 (0.78)	Not available			
Resilience	78.34 (11.52)	80.4(12.8) ^a	-2.06 [-5.00–0.89]	0.16	0.169
Depression	2.32 (3.62)	2.21 (3.60) ^c	0.11 [-0.83–1.06]	0.03	0.813
Anxiety	1.93 (2.84)	1.48(2.60) ^c	0.45 [-0.27–1.18]	0.17	0.217
Stress	3.69 (3.70)	3.79 (4.10) ^c	-0.10 [-1.05–0.85]	0.02	0.831

Cohen's *d*: 0.2 = small, 0.5 = medium, 0.8 = large [108–110]

Although there was no statistical difference between groups, the mean score for anxiety and depression on the DASS-21 was higher than the Australian population mean. Fifteen per cent ($n=9$) of the sample scored above average symptoms of depression. Twenty-three per cent of the sample scored above average symptoms of anxiety ($n=14$) and 16 per cent experienced above average stress symptoms ($n=10$). No statistical difference was found between groups, but the sample reported a lower mean score for resilience compared to that of the US general population.

4.4.1 Pre-existing Factors and Psychological Distress

There were no statistical differences found between fathers and mothers, Aboriginal and non-Aboriginal parents or employed and non-employed parents. Mean scores and standard deviations are presented in Table 4.4. There were no trends found for age and psychological distress, or age and resilience. When comparing the sample by income, no statistical differences were found.

Parents with a history of a diagnosed mental illness had significantly more depression (*mean rank*=43.83, $p=0.03$), than parents who did not have a mental illness (*mean rank*=28.43), more anxiety (*mean rank*=47.58, $p=0.00$) than those without a mental illness (*mean rank*=28.60) and more stress (*mean rank*=45.83, $p=0.02$) than parents without a mental illness (*mean rank*=29.38). In addition, parents with a mental illness had significantly more symptoms of avoidance (*mean rank*=44.25, $p=0.04$) than parents without a mental illness (*mean rank*=28.97).

Parents who had experienced a past traumatic event that had negatively affected their life experienced significantly more symptoms of stress (*mean rank*=35.79, $p=0.02$) and PTSD (*mean rank*=36.22, $p=0.02$), in particular, symptoms of intrusion (*mean rank*=37.64, $p=0.00$) and hyperarousal (*mean rank*=38.10, $p=0.00$). Parents who felt helpless at the time of the event had significantly less resilience (*mean rank*=26.17, $p=0.04$) than those who did not experience helplessness at the time of the event (*mean rank*=37.04). Parents who witnessed the accident had significantly more stress (*mean rank*=36.66, $p=0.05$) and PTSD (*mean rank*=38.38, $p=0.02$), especially an increase of symptoms of avoidance (*mean rank*=39.20, $p=0.01$) and intrusion (*mean rank*=37.38, $p=0.04$).

There was no relationship between factors associated with the burn such as location, mechanism, size, surgical intervention, and parental distress. However, parents of daughters had significantly more anxiety (*mean rank*=33.67, $p=0.03$) and symptoms of avoidance (*mean rank*=33.73, $p=0.03$), with a trend towards having more stress (*mean rank*=33.80, $p=0.06$) than parents of boys.

Variable	Parent		Indigenous status		Employment status		Family income	
	Father <i>M(SD)</i>	Mother <i>M(SD)</i>	Aboriginal <i>M(SD)</i>	Non- Aboriginal <i>M(SD)</i>	Employed <i>M(SD)</i>	Unemployed <i>M(SD)</i>	> \$41,600 <i>M(SD)</i>	≤ \$41,600 <i>M(SD)</i>
PTSD	10.67 (8.76)	13.00 (9.88)	14.82 (9.64)	12.22 (10.40)	11.81 (8.81)	13.13 (10.68)	12.78 (9.46)	11.18 (9.25)
Intrusion	5.67 (4.45)	6.40 (5.49)	5.7 (4.40)	6.32 (5.45)	5.97 (4.89)	6.52 (5.69)	6.78 (5.32)	4.88 (4.50)
Avoidance	5.00 (4.60)	6.60 (5.28)	8.91 (6.32)	5.69 (5.08)	5.84 (4.75)	6.61 (5.65)	6.00 (4.91)	6.29 (5.37)
Hyperarousal	0.63 (0.65)	0.88 (0.73)	0.97 (0.78)	0.77 (0.71)	0.76 (0.67)	0.89 (0.78)	0.85 (0.69)	0.70 (0.66)
Resilience	76.71 (11.86)	79.79 (12.01)	81.50 (10.69)	78.61 (11.44)	80.75 (11.31)	75.43 (13.51)	78.19 (11.31)	78.33 (14.40)
Depression	2.07 (3.50)	1.92 (2.89)	2.10 (2.01)	1.98 (3.25)	2.21 (3.40)	1.61 (2.48)	1.89 (3.19)	2.50 (3.81)
Anxiety	1.29 (2.73)	2.18 (2.88)	2.73(3.07	1.79(2.84)	3.56 (4.79)	2.35 (3.55)	2.50 (3.81)	4.67 (4.79)
Stress	3.18 (3.21)	3.89 (3.89)	2.80 (3.22)	3.70 (3.70)	4.03(4.17)	2.70 (2.49)	4.06 (3.89)	2.59 (2.81)

Note. M=mean. SD=standard deviation. PTSD= post-traumatic stress disorder.

Table 4.4: Mean Differences Between Mothers and Fathers

4.4.2 Relationships Between Outcome Variables

Resilience was negatively correlated with symptoms of PTSD and all three symptoms clusters (intrusion, avoidance and hyperarousal) (see Table 4.5). There were significant positive correlations between symptoms of PTSD, depression, stress, anxiety and resilience, with a particularly strong correlation between PTSD and stress ($r=.708$). Symptoms of depression, anxiety and stress were positively correlated with all adverse psychological outcomes, but were not significantly correlated with resilience.

Table 4.5: Correlations (Spearman's rho) Between Outcome Variables

	PTSD	Intrusion	Avoidance	Hyperarousal	Resilience	Depression	Anxiety	Stress
Intrusion	.937**							
Avoidance	.866**	.741**						
Hyperarousal	.907**	.791**	.693**					
Resilience	-.321*	-.270*	-.224	-.393**				
Depression	.668**	.637**	.531**	.645**	-.143			
Anxiety	.606**	.523**	.606**	.565**	.021	.653**		
Stress	.708**	.679**	.545**	.706**	-.078	.667**	.634**	

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

4.5 Discussion

Findings from this research suggest parents of children who sustained a burn will experience significantly more symptoms of PTSD than the general US population. Although these findings are not statistically significant, parents reported lower levels of resilience and more symptoms of depression and anxiety than adults in a comparative community population. Approximately one in every four parents experienced above average symptoms of anxiety and one in five parents experienced clinically significant symptoms of PTSD. These findings are slightly lower than reported in other studies conducted outside of Australia, where symptoms of anxiety and depression have been reported between 43 per cent [21] and 69 per cent [13], and the most recent study reports

levels of PTSD in mothers to be as high as 50 per cent [12]. However, caution must be drawn when comparing results with other samples, due to differences in sample size as well as outcome measures.

Results from this research show parents experience significant psychological distress within one week of their child's accident. This is a critical time for medical staff to communicate important information to parents regarding their child's health and medical treatments. Psychological symptoms may affect the functioning of parents in many ways, including their ability to absorb information from health professionals about the after-care of their child, highlighting that this acute stage is important for parents. Impairment in functioning from psychological trauma is a significant public health issue for all parties involved [37, 38], and negatively affects quality of life and daily functioning [39–41].

If parents' symptoms of psychological distress are left untreated, it raises the question of how these families will cope three or six months after the event. Research conducted in the UK showed that one-third of parents experienced above average symptoms of anxiety two years after the event [13] and mothers in another study were found to meet diagnostic criteria for PTSD seven years after their child was hospitalised for a major burn [11]. Given the emotional, physical and financial cost of mental illness to the Australian community, it would be beneficial for future parental wellbeing to screen for adverse psychological outcomes and treat these parents of burn survivors, prior to discharge into the community [22]. This has the potential to reduce further development of symptoms of psychological distress and improve health outcomes and quality of life of parents of burn survivors.

No significant differences or trends were found when comparing factors related to the burn such as size, location or mechanism with psychological distress. Whereas factors such as having a daughter, witnessing the event, feeling helpless or having past traumatic experiences significantly influenced symptoms of psychological distress and resilience. These results are in line with the model of paediatric medical traumatic stress, suggesting that the subjective experience of an event has a significantly greater effect on whether it is perceived as traumatic than objective measures of the event [5]. These findings are clinically important and expand on those of Winston et al., who developed the Screening Tool for Early Predictors of PTSD [35]. Identifying important risk factors in parents

allows health professionals to identify higher risk individuals and provide an adequate level of therapeutic intervention.

Stress was directly correlated with all adverse psychological outcomes measured with low levels of resilience associated with increased symptoms of PTSD and stress. These findings suggest that interventions aimed at improving resilience in parents and reducing stress may have a universal effect on the wellbeing of parents. Two evidence-based interventions have been effective for parents of children unexpectedly hospitalised and children with cancer: Creating Opportunities for Parent Empowerment (the COPE programme) [42] and Surviving Cancer Competently Intervention Programme (SCCIP) [43]. Evidence from both programmes strongly supports the benefits of implementing therapeutic interventions for parents as routine, standard care [42–44].

Although results were not significant, parents with lower incomes reported higher mean scores for anxiety and depression and parents who were unemployed had lower mean scores for resilience. These findings are in line with international observations suggesting some of the most vulnerable populations are those from low socio-demographic populations [45]. In contrast, employed parents had more symptoms of depression, anxiety and stress, although it is important to note that there were no statistical differences between the groups. Higher mean scores for employed parents may be due to added stressors caused between juggling the role of a parent with that of an employee, and future research is required to investigate this further.

No significant differences were found between mothers and fathers, suggesting mothers and fathers do not differ regarding their psychological responses. Parental psychological responses are therefore equally important, although the majority of literature focusses solely on maternal wellbeing. Severe and mild symptoms of mental illness experienced by fathers can have serious developmental, behavioural and psychological implications for their children, [18, 19] highlighting the importance of intervention for fathers after their child has sustained a burn injury. There is evidence that the participation in an online support group for fathers of children with brain tumours has significantly improved paternal coping skills [46]. Members of this support group recommend that other fathers would benefit from a combination of online and face-to-face supports [46]. Early interventions that identify and address the mental health needs of fathers are required for

the benefit of fathers, their children and their families. Further research is required to increase our awareness of paternal needs.

To our knowledge, this is the first study to describe the experience of Aboriginal parents of children with burns. For many Aboriginal children and their parents, being away from family and their home or land can be an added stressor [23]. Although there was no statistical difference identified, health professionals should work with Aboriginal parents to develop therapeutic supports that are culturally acceptable and appropriate [23]. Given that 40 per cent of Aboriginal parents in Western Australia live in remote regions with sparse resources, it is vital that primary intervention is provided at the tertiary hospital [22].

4.5.1 Limitations

Due to the nature of the population, a randomised controlled trial or a pre- and post-test design was not possible. This is a difficulty frequently observed in clinically based research. To minimise this effect, the study used normative data from appropriate general populations in the community (Australia and United States). The outcome measures in this study were screening tools and indicate symptoms, not diagnoses. Symptoms of PTSD must persist for a minimum of one month for a diagnosis [47] and parents were assessed within one week of the accident. It is acknowledged that it is normal for parents to be distressed after a traumatic event but it is considered important to screen for symptoms of acute psychological distress to understand the magnitude of distress experienced by parents.

Although there is the potential for individuals with a previously diagnosed mental illness to skew the data, it was considered important not to exclude these parents, as a sample as close to the clinical population as possible was desired. The cross-sectional design prevents conclusions from being drawn about the causal relationships between variables, and future, prospective longitudinal research is required to describe causal relationships.

A stepwise multiple regression analysis would control for co-variance between the predictors, although the small sample size and small number of participants in each subgroup does not meet the guidelines for performing this test. Instead, a more

conservative approach using univariate statistical analysis was performed to describe relationships and avoid under-representing the strength of the relationship between variables. Many comparisons were made, so it is likely that some associations have arisen by chance. However, all are reported, since the power of this study is limited and the researchers did not want to overlook any associations that may prove clinically useful.

4.6 Conclusion

This study reports that parents of burn survivors have low levels of resilience and experience significant psychological distress. There are several important clinical implications from this research. Health professionals should screen parents to identify parents at greatest risk. As part of standard routine care, it is recommended that health professionals assist parents by providing effective, evidence-based interventions aimed at improving resilience and reducing stress to prevent ongoing symptoms. Additionally, future research should explore the impact of burn injuries on fathers, Aboriginal peoples and ethnic minority groups to tailor interventions to meet their needs. Burn injuries can produce long-lasting physical and emotional scars, and it is critical for health professionals to aim reduce the effects of both these components.

4.6.1 Conflict of Interest Statement

No authors had a conflict of interest.

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Chapter 5: ‘*This is Not Just a Little Accident*’: A Qualitative Understanding of Paediatric Burns from the Perspective of Parents

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Foreword

Findings from the first two studies in this thesis demonstrate that burn injuries adversely affect both children and their parents. Research describing the parental lived experience of the burn journey has not been documented and this study aims to expand on the quantitative findings from the previous study. Using phenomenology as a methodological approach allows an in-depth understanding of the lived experience of parents of burn survivors and uncovers aspects of their experience not collected by standardised outcome measures. Findings from this study will facilitate a greater understanding of family needs and stressors, as described from the parental perspective.

5.1 Abstract

Purpose: To describe the experiences of parents of children admitted to hospital for a burn.

Methods: In-depth interviews were conducted with 21 parents (fourteen mothers and seven fathers) of children who had sustained a burn requiring hospitalisation. Face-to-face interviews were conducted six months post-burn, in rural, remote and metropolitan areas. The interview guide explored the overall experience of parents and included probing questions exploring the perceptions, thoughts and feelings of participants. Interviews were digitally recorded and transcribed *verbatim*. Transcripts were analysed according to the seven-step Coliazzi method. Relationships between themes were explored to identify core concepts.

Results: Analysis of interview transcripts revealed three phases that describe the parents' journey: the event, the inpatient phase and the return to community. Within these phases, themes of stressors, behavioural and emotional responses and coping factors were present.

Conclusion: Findings from this research allow health professionals to optimise a holistic clinical service from a consumer's perspective at all stages of the burn journey. These research conclusions could be used for the development of protocols to underpin a comprehensive information and social support management plan for families that would complement and support the surgical and medical treatment plan, providing direction for comprehensive service delivery.

5.2 Introduction

Burn injuries are a serious global health threat to young children [1] and have been described as one of the most painful experiences an individual can encounter [2]. Improved surgical and medical interventions mean more children survive burn injuries [3] and the quality of physical scars is improving [4]. However, it is important that health professionals address not only the physical scar, but also the underlying emotional scars [2]. Providing a voice for the lived experience of consumers is fundamental in identifying gaps within the research, leading to enhanced treatment planning, direction of service delivery and improved health outcomes for all [5].

Existing research suggests that parents experience clinically significant symptoms of PTSD in the acute phase (one to four weeks post-burn) with rates reported between 18.8 per cent [6] to 50 per cent [7]. At three months post-burn, 47 per cent of parents have been reported as experiencing clinically significant post-traumatic stress symptoms [8] and symptoms have shown to persist in some parents, with data suggesting 17 per cent of parents experience PTSD up to seven years post-burn [9]. Anxiety and depression have also been reported to occur with rates of symptoms varying from 18.8 per cent (n=16) [6] to 69.9 per cent (n=16) [10]. Clearly, parents of children who have sustained a burn experience significant psychological distress and require support during this time.

It is evident that burn injuries affect both patients and their families. While there is an increasing body of research describing prevalence rates of psychological distress in parents of children with burn injuries, research describing the experiences of parents has focussed on the child's return to school [11] and family functioning [10], with only one study in the UK investigating the maternal experience [12]. To date, no qualitative research has described the parental journey of having a child sustain a burn injury. This research will facilitate a greater understanding of the needs of families and identify stressors as described from the parental perspective.

5.3 Methods

To understand the experience of parents of children who required hospitalisation for a burn injury, a methodology that allowed the subjective experience to be explored was needed [13, 14]. Phenomenology was chosen as the most appropriate methodological approach for this study [13]. Phenomenological approaches allow the researcher to reveal the lived experience of a phenomenon and its associated meanings through in-depth analysis of individuals' subjective experiences [14]. Phenomenology is particularly applicable when little is known about a specific phenomenon [14], as is the case for parents of burns survivors.

5.3.1 Data Collection

Data was collected from the sole tertiary paediatric hospital in Western Australia, with a catchment area spanning 2.5 million square kilometres. A purposive sample of 21 parents of children who sustained a burn injury requiring hospitalisation for one night or more were recruited [13]. Ethics approval was obtained, and informed consent was given by all participants.

The interview guide consisted of open-ended probing questions that explored the experiences, perceptions, thoughts and feelings of participants [13]. Open-ended questions were asked about the accident, admission to hospital, surgery and recovery. The interview process was piloted with the mother of a 14-year-old burn survivor to ensure the questions and the interview technique elicited information to meet the objectives of the study [13].

Unstructured, face-to-face interviews were conducted with parents six months after the burn injury, at the participants' homes. Socio-demographic information was also collected via a self-report questionnaire consisting of questions on age, gender, employment and ethnicity. It was important that participants felt comfortable and secure in their environment to facilitate confidence in sharing their opinions and experiences [13]. To assist this, the researcher established rapport with patients via phone calls prior to the interviews and conducted interviews within the participants' homes.

The researcher travelled to the participants' homes, including travelling to rural and remote areas, which ensured a sample representative of the clinical population. Interviews lasted a minimum of one hour in length and were digitally recorded. During the interviews, the researcher used a journal to record all non-verbal cues from participants and environmental factors of importance, as well as to reflect on the interview process [13]. Once redundancy in descriptions was reached, recruitment ceased [13].

5.3.2 Data Analysis

All interviews were transcribed *verbatim* and de-identified. Pseudonyms were created to protect the confidentiality and identity of the participants and all interviews were transcribed verbatim. QSR International's NVivo 9 qualitative data analysis software [15] was used to perform data analysis and analysis followed Colaizzi's method of qualitative data analysis [16] (see Table 5.1). This method allowed the researcher to reflect on and interpret emerging themes [16].

Table 5.1: Colaizzi's Data Analysis Framework Procedure [16]

- Step 1. Reading transcripts to acquire a sense of each transcript
- Step 2. Extracting significant statements from transcripts
- Step 3. Formulation of meanings
- Step 4. Organising formulated meanings into themes
- Step 5. Exhaustively describing the investigated phenomenon
- Step 6. Identification of the fundamental structure of the phenomenon
- Step 7. Validating the process by returning findings to participants.

An expert in the field of qualitative research reviewed the transcripts and used the same analysis method to ensure the credibility of the findings. Bracketing was used by the researcher to put aside previous knowledge and beliefs about the researched phenomenon [13]. The trustworthiness of this study was enhanced by an audit trail, member checks with participants and reflective journaling to record field notes and develop perceptions,

questions and reflections of the study progress. Peer debriefing with the co-authors to discuss growing insights of the phenomenon was undertaken [17].

5.4 Findings

5.4.1 Participant Characteristics

Twenty-one parents (14 mothers and seven fathers) of children aged six months to 15 years old who had been hospitalised for a burn injury were interviewed in this study. Total burn surface area estimates for the injuries ranged from 0.5 per cent to 15 per cent with the average size being 4.12 per cent. None of the burns sustained was life threatening and all except two children required surgery. The sample consisted of four mother/father dyads, nine parents who were either married or in a relationship and four single parents.

One parent was Canadian, one was English, three parents were Aboriginal Australians and 16 parents identified themselves as Australian. All but two parents had other children and 15 parents were employed, with the remaining six not currently working. Six parents lived in rural and remote areas of Western Australia, including two parents who lived in a remote Aboriginal community. Nine children sustained burns in rural and remote areas that were at least three hours' drive away from the only children's hospital in Perth.

Analysis of interview transcripts revealed three phases that described the parents' experience of having a child who sustained a burn: the event, the inpatient phase and the return to community (see Figure 5.1). Within these phases, themes of stressors, behavioural and emotional responses and coping factors were present (see Figure 5.1). Coping factors are described as efforts made by parents to reduce stress as a response to stressors in the external environment [18]. All direct quotes are presented in italics and pseudonyms are used.

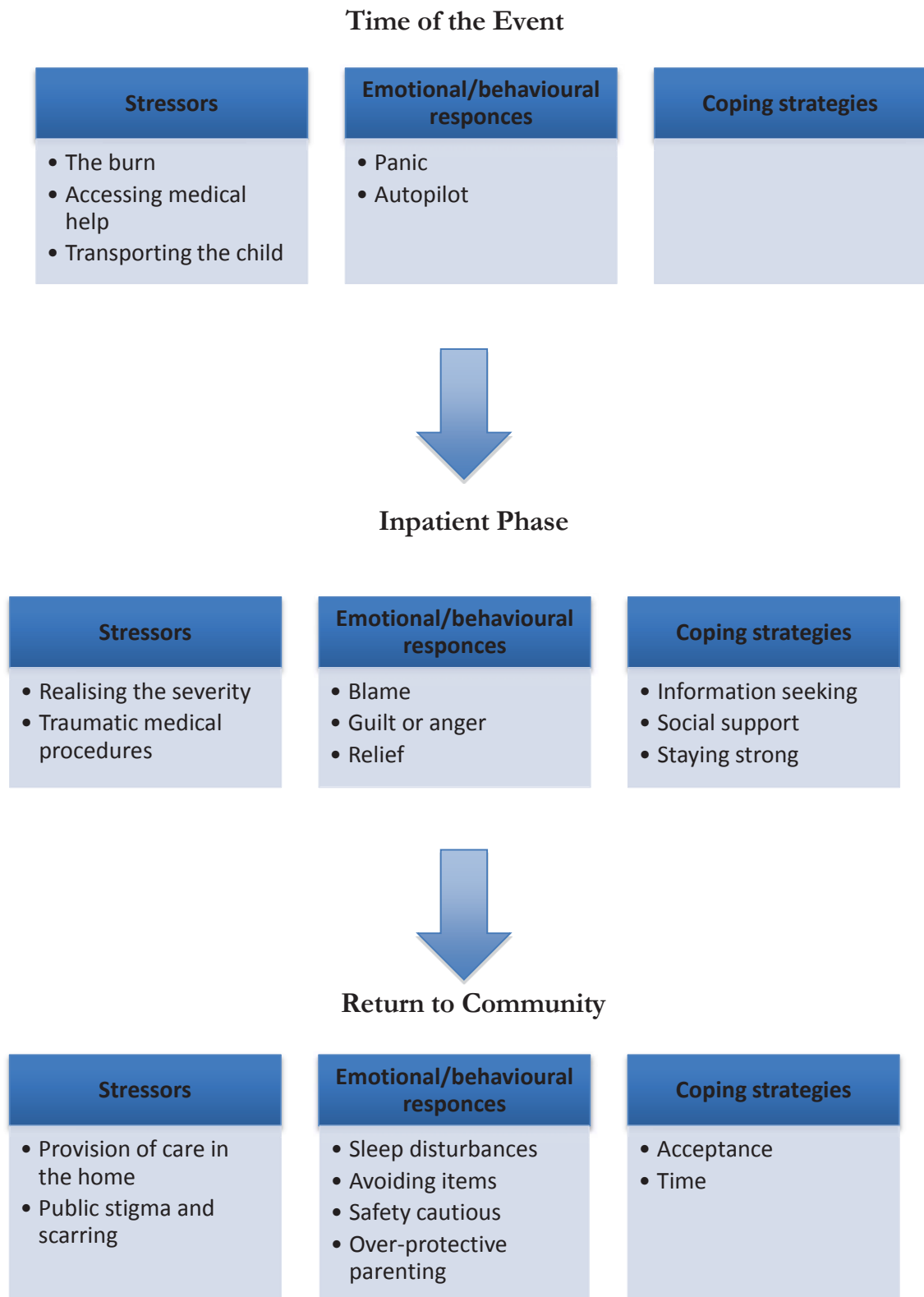


Figure 5.1: Identified Themes

5.4.2 Phase I: The Event

During this phase, two main themes were identified: the accident and accessing medical help.

5.4.2.1 The Accident

For all parents in this study, witnessing their child's burn was extremely traumatic, 'horrific' and 'something [they would] *never forget*'. Parents described feeling panicked as they heard their child's 'blood-curdling screams'. One mother witnessed her child 'on fire, running around the yard'. Several parents described the point where they saw 'skin peeling off' as the point at which they panicked: 'As I put his foot under the water, the top layer of his skin just peeled away, and I guess that was a bit of a shock to see that, and I knew it was bad'.

The realisation that 'this [was] *not just a little accident*' resulted in a state of 'shock', where parents described themselves as functioning on 'auto pilot' and 'going into automatic'. Parents experienced considerable stress at this point, but were unable to process their emotions, suppressing their emotional responses until their child had received medical attention:

I was absolutely panicked and horrified, but nothing really registered until I was in the hospital and [my child] had sort of calmed down a bit, then I broke down.

5.4.2.2 Accessing Medical Help

The immediate priority for parents after the burn was accessing medical attention for their child. Parents who were on their own with their child at the time of the burn described the drive to the hospital as 'extremely stressful'. Trying to drive while their child was 'screaming, shaking and hysterical' in the back of the car was very difficult. Several mothers described how they drove at least three hours with their child in the car to reach the hospital.

Those who called for an ambulance reported that the support from paramedics at this stage provided relief, as ‘*it was more than [they could] deal with on [their] own*’, and parents felt ‘*reassured*’ that their child was receiving medical attention. As one father described:

The minute after it happened, that was the worst for me, because the burn hurt, and there was no one to help us, and I couldn’t change it. Once the ambulance came, and I heard the helicopter coming, I sort of felt a big sense of relief, because I knew it was bad, but I knew he was going to be okay.

5.4.3 Phase II: The Inpatient Phase

This phase consists of three main themes: 1) relief to know your child is in the best hands; 2) realisation of severity; and 3) traumatic medical procedures (see Figure 5.1). Parents reacted to the stresses of the inpatient phase by using the coping strategies of information seeking, using social supports and staying strong for your child (see Figure 5.1). Self-blame was a strong emotion felt throughout and resulted in feelings of either anger or guilt.

5.4.3.1 Relief to Know Your Child is in the Best Hands

Participants spoke of the ‘*enormous sense of relief*’ they felt when they reached the Burns Unit at the tertiary hospital. At this stage, parents felt they were able to hand over some of the responsibility for the care of their child because ‘*the consultants took control*’ and their child was now in the ‘*best hands*’. Parents described their confidence in the hospital system, which they felt was able to provide the ‘*very, very best treatment on an international level*’. As one father explained:

Because all you’re looking for is to know that you’ve done the best by your child, and if you’re given that comfort to some degree, you can relax.

5.4.3.2 Realisation of Severity

The majority of parents described how initially they underestimated the severity of the burn injury. The admission of their child as an inpatient to the Burns Unit resulted in the realisation for parents that ‘*this wasn’t just something that was going to be fixed in the*

next few hours', and 'the severity of [the burn] hit home'. Many described how shocked they were to discover their child required a skin graft. As one mother described:

Then for [the doctor] to say 'That needs a skin graft and I'll do it this afternoon', it was like, we hadn't prepared our son for that. We weren't prepared for that, and it was a shock.

5.4.3.3 Traumatic Medical Procedures

Parents reported that the 'worst' part of the whole experience was watching their child go under a general anaesthetic. While they 'knew it had to be done', parents described this as a point where they 'broke down', 'couldn't stop crying' and as 'one of the hardest things I've ever had to do'. One mother described her thought process as she watched her child prepare for surgery:

The thought of having a three-year-old girl going under an anaesthetic and having skin grafts done scared the hell out of me ... there's that part of you that's like, 'She's too little. She shouldn't be doing this. I shouldn't be here, putting her under an anaesthetic and going through all this stuff'.

Dressing changes were a source of trauma for parents as they described watching this process as 'horrible' and 'horrific'. Many parents reported psychological, somatic symptoms, feeling 'physically sick' and 'nauseous' as they 'struggled to hold [their child] still'. Watching their child 'screaming' during dressing changes produced a sense of guilt for many parents:

So every time he had the dressings done, I had to remember the accident, and I kept thinking, what have I done to my baby? Because I was the one with the tea, ultimately, and I just thought, if I didn't have the tea ... If, if ... what if?

The trauma of witnessing their child in pain during dressing changes was described by parents as something they would 'never forget'. Mothers described reliving the experience of seeing nurses 'popping blisters, cutting skin and pulling it off, over and over again in [their] mind[s]'. Some parents described reliving these experiences up to six months after the injury.

Removing dressings in the bath was described by parents as very ‘traumatic’ for their child. Parents explained the rising fear in their child as they anticipated their dressing change: ‘He would hear all the baths going on down the hall, all the screaming and he knew his turn was next’. Several children were described as avoiding baths once discharged home. As one mother related:

There was a long time where she wouldn’t have a bath, because when she had the bath and we had to take the dressings off in hospital, that was a very painful experience, so there was a long time, probably about three months, where she would not have a bath.

5.4.3.4 Parents’ Responses

5.4.3.4.1 Information Seeking

Parents described the importance of information and ‘knowing what was happening next’ in the inpatient phase. However, parents commonly expressed ‘frustration’ when they ‘didn’t seem to be getting all the information’. Not knowing what was coming next enhanced feelings of ‘panic’, ‘stress’ and ‘anxiety’. As one mother explained:

So, for me, it came down to the amount of information I had about what was going on, which was directly related to how calm or how upset I became.

Not receiving enough information generated considerable anguish and frustration for parents. Parents reported wanting to know more about their child’s progress, rehabilitation and how to talk about emotions with other family members. When parents felt as if they were ‘not being told’ what was happening next, it left them feeling unprepared and as though things were ‘coming out of the blue’.

When reflecting on their experience, most parents felt that they would have coped better had they known more about their child’s condition and treatment. Two mothers described their experiences:

No one said anything, and then [a nurse] gave me a card and said, ‘Come back with him fasted’. And I was like, ‘Fasted. What for?’ And they’re like, ‘Oh, he’s just got to fast. That’s all I know’. And I eventually walked out bawling my eyes out, because I thought, ‘What the hell is going on?’

If I'd had the information [that he was having an operation], I could have dealt with it. I could have been on the phone to a friend and said, 'Could you sit with me?' Just so that I've got somebody to talk to and take my mind off it. But, I didn't have the opportunity to do that, because I wasn't told.

In contrast, having information was described as alleviating anxiety about their child. Parents felt that if they knew what was happening next they felt 'calm', 'in control', and the situation was 'easier to deal with'. While several parents recognised that too much information may have led to 'panicked parents', the majority felt that they would have been able to 'handle it' and would preferred to know more, rather than less.

Information was important to parents in being able to arrange for the care of other children and to 'keep other family members posted'. Not knowing what was happening resulted in stress:

I found out that we weren't going home, so all that length of time not knowing made me feel anxious. I had other things I needed to sort out. I needed that information to know what to do with everyone else, because it wasn't just [Sally] that got burnt ... I had friends with the children, the other children with Mum and Dad, and everyone just wondering what was going on. So having that information would have been helpful ... I was worried about everyone else.

5.4.3.4.2 The Importance of Social Support

For all parents in this study, social support was important in facilitating coping, with many parents reporting that they 'could not have done it on their own' and that, 'it was real relief to know that I would have [my partner] there to help'. Parents described the importance of having someone to talk to 'to take their mind off things'. As one mother described:

So, it was good that I had [my husband] and I think if I didn't have him, I would have fallen apart. I would have really needed somebody to have come and talked to me.

Absence of support was associated with feelings of isolation and loneliness, with some parents describing feeling 'scared, because I didn't have anybody to talk to throughout

the day'. Staying in touch with family members was particularly important for parents who lived in rural or remote areas. In particular, Aboriginal parents described '*communication with family [as] the key*', because culturally it is '*important to be around family all the time*'. One Aboriginal father described how it was '*important to talk [to family members] on the phone every day*'.

Parents described experiencing difficulty solely managing both the emotional and practical aspects of their child being in hospital. The absence of social support contributed to increased stress, as a mother described:

I just didn't think it was going to be that bad and then realising how bad it was, and he needed a skin graft, and it was a lot to take in, because I was by myself with him.

The absence of social support meant that it was hard for parents to meet the needs of their child and their self-care needs:

And I remember when I was there, in the hospital, it was hard for me to leave him and go and get a drink and stuff, because I was travelling on my own.

The experience of having a child with a burn also added pressure to relationships. Parents reported how the '*extra pressure*' of having a child in hospital and feeling '*too stressed out to lean on each other*' led to greater partner conflict. Mothers particularly described feeling as if they '*neglected*' their husband and other children as their '*whole attention*' was consumed by their child in hospital:

You think the other children aren't really getting their fair share of attention. It's okay for a week, but doing it for a longer period, you wonder does it affect them?

5.4.3.4.3 Staying Strong for Your Child

Parents reported having to '*stay strong*' for their child. Parents felt it was important not to let their child see them upset, with parents putting on a '*brave face*' in front of their child and '*only breaking down when I had to*'. As one mother described:

There was times where I got home and I screamed and yelled and cried and whatever, but I tried to do a brave face in front of her. I thought 'I've got to

make sure that she knows everything will be okay'. So that she didn't get worried.

During the inpatient phase, parents struggled to cope with a barrage of emotions. Staying in hospital was associated with feelings of loneliness, both for the parent who stayed overnight with the child and the parent (mainly fathers) who were unable to be with their child in hospital. The disruption that the inpatient phase caused to the family unit was described as 'horrible', with one father describing how he turned to substance use to cope:

Because when I was home on my own, when they were in hospital, the only thing I could do to kill time was substance use, and that was bad. It was not a good time.

5.4.3.4.4 Blame

During the inpatient phase, parents reflected on the causes of the accident. They attributed blame to either themselves or others. Blaming others for the accident resulted in feelings of resentment and anger, while blaming themselves led to feelings of guilt.

Parents who blamed their partner for the accident described feeling resentment towards them. Some parents said that it was something they 'wanted to talk about [with their partner] but never did'. Parents who blamed someone else for the accident felt a great deal of anger and were unable to process this anger during the inpatient phase:

I can honestly say I've never been so angry in my life.

I was so angry, I couldn't even look at his Dad. It took me weeks. I was scared if I spoke to him I would say, 'It was your fault, you shouldn't have done this, you shouldn't have bought the bikes' ... I was just so scared that if I actually spoke to him, it would all just come blurting out.

Parents who blamed themselves for the accident described feeling intense guilt. The majority of parents who did not blame another person for the accident blamed themselves. Many parents described constantly ruminating on thoughts of guilt:

I don't think I've ever felt so guilty about something ... I thought, I let this happen, how could I do that?

I'll never completely forgive myself for it, because it's something that shouldn't have happened.

Many mothers questioned their competence as a parent, 'Am I a bad mother?' They struggled to tell people about the event, as they felt their role as a mother was being judged:

I was still feeling really terrible and then if someone asked me what happened, telling them again, it obviously makes you feel worse, and as much as you know people are trying to be honest, saying, 'It's not your fault', you think to yourself, 'Do they really think that?', especially when my own mother-in-law said it was my fault.

5.4.4 Phase III: Return to the Community

The findings identified five themes in this phase including returning home, changes in the child, changes in the parent, scar management and the long journey of recovery. Within these themes, the identification of specific stressors, behavioural responses and coping strategies are described (see Figure 5.1).

5.4.4.1 Returning Home

Returning home after the burn was described by some parents as a 'challenging time'. Parents reported being 'surprised' to be discharged 'so early' and felt 'concerned' and 'worried' to be going home. Many parents were apprehensive about managing their child's pain levels at home and worried about how they would stop their child being too active:

I did feel a bit worried coming home, because they were saying, 'His graft needs to take, and you can't bump it, or jump', and I know what he's like at home. I thought, 'How do I control it all?'

In contrast, other parents felt a yearning to go home and return to a sense of normality. Parents described feeling more ‘*relaxed*’ at home and ‘*wanted to return to normal routines*’. Some parents described the driving force for wanting to be discharged was to have their family ‘*back together*’ and to return to normal family life.

Many parents felt a lot of ‘*pressure*’ at this stage, as the responsibility for their child’s care was placed back in their hands. One mother described, ‘*but at two [years old], it’s one hundred per cent my responsibility that she is okay*’. Parents reported that the pressure of ensuring they were providing the correct after-care for their child once discharged, started to ‘*weigh down on [them]*’ and they began questioning their ability to care for their child:

What else am I doing wrong, or not right? What else am I doing that’s then going to affect her? This is going to affect her for the rest of her life if it’s not taken care of and looked after... so I need to know everything there is to make sure that that doesn’t affect her growing up.

5.4.4.2 Changes in the Child

It was after being discharged that parents report noticing changes in their child’s behaviour. In the short-term, mothers felt their child became more ‘*clingy*’, ‘*fearful*’, ‘*withdrawn*’ and ‘*cautious*’. Children became considerably more dependent on their mothers, increasing the stress mothers experienced, which affected their ability to undertake daily activities and routines:

It would have probably all fitted into that three-month period, but her being clingy like that, contributed to me not going out much.

For probably months after, I would be the only one that could put him to sleep and anything, and we’ve only just stopped being able to do that—probably in the last two months. Before then he was very much, ‘Mummy, Mummy, Mummy’, all the time.

No, just clingy. Like wherever I was and if I’d put him down, he’d sook, grab onto my pants, or my shirt. He was never not with me. Ever.

Sleep disturbances among children were common in this phase, with parents describing that since the accident: *'he's not slept a night through'*. Some children were waking *'three times a night'*, with younger children requiring *'a cuddle, or a bottle'* to go back to sleep and an older child sleepwalking every night since the accident.

Participants spoke of their child being more *'danger conscious'*. The majority of children were reported to avoid *'hot cups of tea'*, *'hot baths'* and *'anything heat-related'*, with a parent describing their child as having an *'over-sensitive level of awareness about heat'*.

One mother described how her child now associated heat with pain:

But, in regards to hot coffees and hot items and stuff like that, yeah, she's a lot more aware of what can happen and she always says, 'Oh, that can hurt'. You can see it in her face that she realises that hot means a lot of pain and she doesn't want to go through that again.

5.4.4.3 Changes in Parents

Several parents described difficulties sleeping at night. Parents reported *'[finding] it hard to sleep, relax and get comfortable, because I was always thinking, "Is she okay, or is she going to wake up and scream?"'* Parents found themselves getting up in the middle of the night to *'make sure [their child] was okay'*. Nightmares experienced by parents painted vivid images of their child *'losing a limb'*, *'driving to the hospital'* and *'[of their child] crying in pain'*. One mother described having ongoing dreams about her child's dressing changes:

Like, as soon as I closed my eyes, all I could see was that, and that would be the dream straightaway.

Nightmares and sleep disturbances in participants tended to diminish by three months after the accident. This suggests that with time, parents were able to process the traumatic aspects of the burn injury.

Parents reported avoiding or removing items that caused the accident. Examples of this included: *'I will not cook her noodles that way'*; *'We never went back to the farm ... so we sold it'*; and *'I've changed all the coffee cups in the house'*. One mother described being unable to go back onto the treadmill that caused her child's burn:

I still feel bad about it, because I was the one on the treadmill and I haven't used it since then. It's just sitting in the corner. I don't even want to use it.

Parents felt they became 'overprotective' of their children. Parents described themselves as not being able to let their child out of their sight and as going 'through the whole checklist before he goes out'. Some parents reported changing their style of parenting because of the accident:

Yeah. I am definitely more emotional. I watch the kids a lot more. Like I've almost become a helicopter parent, which is annoying because I never wanted to be like that.

The return to daily life in the community caused parents to think about 'what if' scenarios, and how they would cope if one of their children were injured again:

I just wanted everything to be safe, and nobody to get hurt, because I probably couldn't have dealt with somebody falling off their bike.

Now that it has actually happened, I think about even worse things than burning, and it's what would I do if something like that occurred, and how would I deal with it?

5.4.4.4 Scar Management

Once they had returned to the community, parents described noticing 'people staring' at their child's pressure garment and this made them feel 'self-conscious for [their child]'. Parents expressed that they felt 'sorry for them when people are looking'. One mother described her attempt to shelter her child from people's stares:

And it happens a lot, you'd see people looking, and he would sense that. I'd go, 'Look at this, let's go here', and try to keep his eyes off what people's faces were doing. Because you could clearly see it.

Gender differences emerged in relation to the long-term meaning of the scar. Fathers reported being 'concerned' about how the appearance of the scar would affect their daughter as she grew up and hoping 'that the damage was not going to be so permanent'

or hoping that she will not be ‘discriminated against’ because of her scars. A father described his fear of his daughter’s future body image:

The only thing that tends to run through my mind is, I just hope these scars really do fade as she gets bigger. That’s the only thing. My worst thought is her being a young woman and having this freak out, or feeling revulsion at her own body and the way she looks.

In contrast, parents of boys described their child as being ‘proud of their scar’ and wearing ‘their pressure garment like a trophy’. Mothers reported their sons were excited to return to school to show their friends their scar:

I think they feel like they’ve survived, you know, that sense of victory and in actual fact, he wears his scar like a badge of honour.

Oh, he was happy to show it off. In fact, when other kids show that they’ve got a sore knee or something, he’s very forward in saying, ‘Oh, check out mine’. I guess boys are quite proud of their little war marks.

5.4.4.5 The Long Journey of Recovery

Parents at this stage were able to reflect on what they called their ‘journey’, describing it as an experience ‘quite distinct from a lot of other things you go to hospital for’. Parents described how they had come to terms with knowing ‘there’s no quick fix for this, you’re in for a long haul’ and that ‘burns [are] something you’re going to stick around as an outpatient for ... being discharged is part of a longer journey, really’.

Acknowledging the need to ‘accept the accident’ and ‘learn from it’ was important in being able to move forward in their journey:

I mean, the initial part of it’s bad when you’ve got the trauma, the accident, the grief and the loss and all that ... but it’s all a natural progression once you’ve kind of accepted it.

I would love to be able to have that something that happened completely disappear and not happen at all, but it happened, there’s nothing we can do about it now, except for do what they tell us to do to help the scarring.

Time emerged as an important factor in families coming to terms with the accident and the injury. The time point three months after the accident was deemed to be a critical ‘turning point’ for many parents:

That first three months we were dealing with how the burn was healing, you know, all that emotional stuff was very raw still, whereas six months down the track everyone seems—maybe not over it, but are reconciled with it.

Well, it’s probably, definitely taken six months and it will be different again in 12 months probably, but it definitely took a big chunk of three months to get over the rawness, and now it’s not so in-your-face, six months down the track.

Some parents expressed that the journey did not completely resolve but became part of them. One mother described how, for her son, having a burn injury was a lifelong journey:

One of the kids said, ‘Have you still got your burn’, because they noticed he wore his skins. And he said, ‘Yes, I’ll have it forever’.

5.5 Discussion

The aim of this study was to describe the experience of parents of burn survivors. Data analysis revealed that the parents’ experiences reflected a journey represented by three phases: the event, the inpatient phase and the return to the community. Within the three phases, themes were identified. These themes represented the external stressors, the emotional and behavioural responses and coping strategies.

The three phases identified in the parents’ journey provide support for the theory of the model of paediatric medical traumatic stress [19]. This model was conceptualised from quantitative findings and clinical observations and describes paediatric medical traumatic stress at various phases of treatment and illness progression [19]. The patient and family’s experience of trauma is described as moving through three phases: Phase I, the occurrence of the potentially traumatic event; Phase II, early (acute), ongoing and evolving traumatic stress responses; and Phase III, the longer-term traumatic stress responses [19]. Findings

from this research provide qualitative evidence to support this model and constitute the first study to describe qualitatively the context of this experience. This research has also identified changes in coping strategies and behavioural responses across three phases. Collectively, the findings suggest that the support and service needs of parents change throughout their experience of having a child with a burn injury.

During the first phase of the parental journey, parents reported either panicking or going into 'auto pilot' to take charge of the situation. Panicking at the time of the event has been shown as relating to the development of PTSD in adults following a motor vehicle accident or assault [20]. It has been reported that the Western Australian public have limited education regarding the correct first aid for burn injuries [21]. If parents are in a panicked state at this time, the provision of first aid may be even further compromised. Support provided by paramedics and family was an important factor in reducing feelings of panic at the time of the accident. These findings highlight the importance of seeking social support as well as medical intervention during the time of the event. This is particularly important for families who may live at least three hours away from the nearest hospital.

Findings from this research indicate that the witnessing of medical procedures during the inpatient phase (Phase II) can produce strong emotional and physical responses in parents, including feeling nauseous and having nightmares. The education and preparation of parents prior to witnessing these potentially traumatic medical procedures may help to alleviate the levels of distress they experience [22, 23]. Research suggests that parents are frequently not given advice on how to support their child during medical procedures and this constitutes a source of stress for parents [15, 24]. For parents in this study, provision of information was identified as having a calming effect.

Parents who believed they did not receive adequate information reported feeling anxious, worried and stressed. Research investigating parent perceptions of paediatric burn dressings showed that 27 per cent of parents reported that medical procedures were not explained to them [15]. This finding is consistent with parents of children with acute illnesses who report requiring more verbal and written information about all aspects of their child's care [25]. Explaining medical procedures to parents and supporting them with techniques to reduce anxiety during these procedures may help minimise their

distress [22, 23]. The present research indicates that each unit would benefit from the implementation of a protocol for educating parents in child-management strategies as a standard, universal procedure.

Several mothers in this study described feeling responsible for the accident occurring and consequently blamed themselves. This led to feelings of guilt, consistent with previously reported findings [6, 11, 12]. Guilt has been associated with long-term symptoms (up to ten years after the event) of PTSD in mothers of children with burns [26]. Screening parents for excessive symptoms of guilt and blame in the inpatient phase may assist to identify the potential for ongoing, long-term symptoms of PTSD. Support programs aimed at assisting parents to process feelings of guilt, blame and anger have been shown as effective for parents of children with severe disabilities [27]. Future research should consider evaluating similar programs for parents of children with burns.

Coping is used in times of increased stress to regain a state of equilibrium to continue to function in daily roles, routines and challenges in life [28]. Successful coping and adaptation involves application of functional, habitual coping strategies, drawing on sources of social support and individual personality strengths [28]. In times of crisis, stress and anxiety can overwhelm an individual's capacity to access functional coping, resulting in the use of dysfunctional coping strategies and the emergence of unconscious, immature defence mechanisms [28]. Psychological disorganisation and or disintegration can occur, lowering an individual's resilience for future stress [28].

The parents studied in this research identified information seeking and social support as effective coping strategies. Other research has shown that social support and planful problem solving in the acute period have a positive influence on functional outcomes in children [29] and transitioning to school [11]. To minimise the development of adverse psychological symptoms, it is imperative parents employ and utilise identified beneficial coping strategies. Health professionals can assist parents to harness their available social networks and promote effective coping and adaptation.

High psychological vulnerability and evidence of acute stress disorder was reported by parents in the first three months post-burn. Symptoms were reported to subside from three

months to six months post-burn, with no evidence of the development of PTSD. This research has determined the zero to three-month period as a high risk phase for parents.

Returning to the community was the third phase described in the parental journey. Relief associated with commencing normal routines can be overshadowed by the responsibility parents feel to ensure they are able to provide the best after-care for their child. Parents also described a loss of confidence in parenting skills. Supporting parents as they make this transition from hospital to community is important, especially for parents living in rural areas [30]. Discharge planning is an essential part of this process and qualitative evidence suggests parents feel isolated at this time and do not think they have adequate information about their child's condition [25]. More emphasis should be placed on communication for discharge planning to ensure parents are confident in managing their child's injury after leaving the inpatient unit [25].

Parental activities of daily living, routines and roles were affected after their child's discharge. Parents described functional implications such as avoiding situations, sleep disturbances, changes in their parenting style and behavioural changes in their child. Little research has investigated the functional impact of paediatric burns on the lives of parents. Parental functioning is an important aspect to consider for future research in this area.

Although the numbers were small, this is the first qualitative study to include Aboriginal parents ($n=3$) of burn survivors. For many Aboriginal children and their parents, being away from family and their home or land is an added stressor [31]. 'Attachment to country' is a positive coping strategy that is lost with hospital admission. Health professionals should be aware of these added stressors and work with Aboriginal parents to develop therapeutic supports that are culturally acceptable and appropriate [31]. Given 40 per cent of Aboriginal parents in Western Australia live in remote regions with sparse resources, it is inevitable that primary intervention is provided at the tertiary hospital, as there are limited services in these remote areas [32].

As advances in medical care continue to improve outcomes for burn patients, an understanding of the needs, psychological wellbeing and capacity of families is important. This research has several clinical implications. Health professionals need to be able to provide support to parents and families not only during the inpatient phase, but also when

children are discharged. Support should be aimed at enhancing information provision and minimising the potentially traumatic aspects of medical procedures. To improve information provision, resources such as educational programmes on electronic devices as well as written pamphlets about the physiological and psychological process of burn injuries could be provided, complementing verbal information. It is important these educational resources are culturally appropriate and are accessible for rural patients once discharged to the community. Best-practice guidelines from a recent systematic review report that information should be presented verbally with written and visual cues to enhance recall [33].

5.5.1 Limitations

This study involved one interview six months post-burn, whereby parents were questioned about three time points. Future research would benefit by interviewing participants at three time points, creating a greater understanding of each phase.

5.6 Conclusion

Findings from this research allow health professionals to optimise a holistic clinical service from a consumer's perspective at all stages of the burn journey. These research conclusions could be used for the development of protocols to underpin a comprehensive information and social support management plan for families that would complement and support the surgical and medical treatment plan, providing direction for comprehensive service delivery. With improvement in the surgical outcomes for burn survivors, the next aim is to minimise the subsequent development of negative psychological outcomes, thereby improving quality of life for parents, families and patients.

5.6.1 Implications for Rehabilitation

- The findings identified changes in coping strategies and behavioural responses across three phases of the parental journey.
- Collectively, these findings suggest that the support and service needs of parents change throughout their experience of having a child with a burn injury.

- Findings from this research allow health professionals to optimise a holistic clinical service from a consumer's perspective at all stages of the burn journey.
- These research conclusions can be used for the development of protocols to underpin a comprehensive information and social support management plan for families that would complement and support the surgical and medical treatment plan, providing direction for comprehensive service delivery.

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5.6.3 Conflict of Interest

No authors report a conflict of interest.

5.7 References

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Chapter 6: Paediatric Healthcare Professionals: Relationships Between Psychological Distress, Resilience and Coping Skills

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Foreword

Children, parents and health professionals are interconnected in a professional relationship and health professionals are exposed to paediatric trauma on a daily basis. The first three studies in this thesis have found that exposure to paediatric burns can adversely affect children and their parents. However, the effect this has on paediatric multidisciplinary teams is unknown. This study aims to understand how paediatric medical trauma impacts health professionals' wellbeing and which risk factors are associated with poor health outcomes. Acknowledging the impact of paediatric medical trauma on health professionals' mental health is an important step towards maintaining a healthy workforce and will lead to improvements in the therapeutic relationship between children, parents and staff.

6.1 Abstract

Aim: To investigate the impact of regular exposure to paediatric medical trauma on multidisciplinary teams in a paediatric hospital and the relationships between psychological distress, resilience and coping skills.

Method: Symptoms of post-traumatic stress disorder (PTSD), secondary traumatic stress, depression, anxiety, stress, burnout, compassion satisfaction, resilience and coping skills were measured in 54 health professionals and compared with published norms.

Results: Participants experienced more symptoms of secondary traumatic stress ($p < 0.01$), showed less resilience ($p = 0.05$) and compassion satisfaction (≥ 0.01), more use of optimism and sharing as coping strategies and less use of dealing with the problem and non-productive coping strategies than comparative groups. Non-productive coping was associated with greater secondary traumatic stress ($r = .50$, $p = 0.05$), burnout ($r = .45$, $p = 0.01$), PTSD ($r = .41$, $p = 0.05$), anxiety ($r = .42$, $p = 0.05$), depression ($r = .54$, $p = 0.01$), and stress ($r = .52$, $p = 0.01$). Resilience was positively associated with optimism ($r = .48$, $p = 0.01$). Health professionals <25 years old used more non-productive coping strategies ($p = 0.05$), less 'sharing as a coping strategy' ($p = 0.05$) and tended to have more symptoms of depression ($p = 0.06$).

Conclusion: Paediatric medical trauma can adversely affect a health professional's wellbeing, particularly those <25 years of age who make less use of positive coping strategies and more use of non-productive coping. These findings will assist the development of effective and meaningful interventions for health professionals working in paediatric hospitals.

6.2 Introduction

On a daily basis healthcare professionals are exposed to traumas such as witnessing acute medical trauma, performing painful medical procedures and dealing with end-of-life scenarios. With the pressures associated with large, complex caseloads, staff members are often unable to process their reactions [1]. Paediatric medical traumatic stress refers to the psychological and physical responses experienced by children and their families as a result of encountering pain, injury, serious illness and medical procedures, which include invasive and frightening treatments [2].

The impact on health professionals caring for children and families is unclear. Healthcare professionals working with traumatically injured adults are at increased risk of experiencing negative psychological effects [3–5], but research investigating the wellbeing of multidisciplinary teams within paediatric hospitals is scarce. Children are often described as a vulnerable population in society. Paediatric health professionals recognise this status and that, in the context of trauma they may be at a greater risk of experiencing psychological distress. With a growing national shortage of healthcare professionals [6], it is vital that efforts are made to understand and explore the factors affecting the mental health of paediatric multidisciplinary teams.

Various terms have been used to describe the effects of occupational exposure to another person's trauma: 'secondary traumatic stress', 'compassion fatigue', 'vicarious trauma' and 'burnout'. These terms refer to the cumulative effects of exposure to trauma, each covering a subtly different concept [7]. STS is the occurrence of emotional responses and symptoms associated with working with patients who have experienced trauma [7]. Symptoms of STS are similar to those of PTSD and may include fear, sleep difficulties, and avoidance of intrusive, clinical images. STS is sometimes used interchangeably in the literature with the term 'compassion fatigue' [7], but compassion fatigue differs slightly to STS, as it also relates to the inability to provide empathy towards patients. In contrast, 'compassion satisfaction' is the positive feelings associated with helping and caring for patients [7]. 'Burnout' refers to emotional exhaustion and a decreased sense of accomplishment with professional tasks [7]; it is not specific to trauma work and can occur in any profession.

Three relevant studies in paediatric hospitals have been conducted in North America. A study found staff were at risk of experiencing compassion fatigue, burnout and STS, which were associated with increased length of employment and blurring of caregiver boundaries [5]. The other studies reported that females, third-year registrars and health professionals living alone or not in a relationship were at greater risk of developing increased symptoms of burnout [6, 8]. However, the literature in this area is sparse and often focusses on one aspect of exposure to trauma, such as symptoms of STS or burnout. To understand the magnitude of the problem, it is necessary to build on this North American work by measuring prevalence rates of several facets of sub-optimal mental health, including depression, anxiety and stress regarding all members of multidisciplinary teams and examining the relationship between these factors.

Further investigation into pre-existing factors is also required to develop screening tools aimed at identifying individuals at greatest risk. To develop interventions to maintain psychological health, it is important to understand the potential barriers and facilitators to developing psychological distress.

Resilience refers to the capacity to positively adapt and cope despite adversity [9]. To date, no research has explored the role of resilience in buffering against psychological distress in multidisciplinary teams within paediatric hospitals. It is important to understand if resilience and positive coping strategies play a role in minimising the impact of exposure to paediatric medical trauma, and whether these factors influence an individual's vulnerability to psychological distress. This knowledge would underpin the development of interventions for health professionals working in paediatric multidisciplinary teams.

This study posed three hypotheses: (a) there is a difference between the current psychological profiles of healthcare professionals and that of comparison groups; (b) pre-existing factors are associated with psychological responses in health professionals; and (c) relationships exist between symptoms of psychological distress, resilience and coping strategies.

6.3 Method

6.3.1 Participants and Procedure

Staff members at Princess Margaret Hospital, Western Australia, working with children with severe acquired brain injury or a burn injury were invited to participate in the study. Princess Margaret Hospital is the sole tertiary paediatric hospital in Western Australia. Participation was voluntary. All 68 eligible staff members were invited to participate and 54 (80 per cent agreed).

The Burns Total Care Unit had 291 admissions in 2011 and the Department of Paediatric Rehabilitation admitted 55 patients with acquired brain injury and spinal injury. Both units admit patients with high injury severity scores on a regular basis, suggesting staff are exposed to medical trauma daily. Staff were divided into two trauma exposure categories: direct exposure and indirect exposure. Those directly exposed had contact with both patients and family members, while those indirectly exposed had contact only with family members. Ward clerks represented the only group with indirect exposure to trauma in this sample. Staff recruited in this sample worked either on the Burns Total Care Unit or in the Department of Paediatric Rehabilitation, but not both. Both units are similar in that they have a high turnover of patients with high injury severity scores, staff on both units are offered the same support resources, work in multidisciplinary teams and have similar demographic profiles.

Ethics approval was received from the Ethics Committee of Princess Margaret Hospital (Project 1855) and Edith Cowan University and all participants provided informed consent.

6.3.2 Measures

Several tools were selected to measure the various facets of the potential impact of paediatric medical trauma. All are screening tools and cannot provide a definitive diagnosis.

6.3.2.1 Resilience

The 25 items of the Connor-Davidson Resilience Scale (CD-RISC) are each scored on a 5-point scale, with higher scores indicating greater resilience levels [10]. The CD-RISC has sound psychometric properties, demonstrating good internal consistency (Cronbach's α 0.89) and test re-test reliability (intra-class correlation coefficient of 0.87) [10]. As no data has been collected on the Australian general population, comparisons were made with normative data from the US general population ($N=577$) [10].

6.3.2.2 Post-Traumatic Stress Disorder

The widely used 22-item Impact of Events Scale—Revised (IES-R) [11] represents all DSM-IV symptom clusters for PTSD. Good reliability has been reported with Cronbach's alphas ranging from .85, .88, .90 and .95 for each symptom cluster [12]. Scores can take values 0–12 with higher scores indicating greater distress. No data has been collected on the Australian general population; comparisons were made with 138 adults in the US general population who had no trauma history [13]. To enable comparison between the two populations, scoring according to the earlier version of the assessment (Impact of Event Scale) was used. Scoring for the subscale hyperarousal was according to the IES-R.

6.3.2.3 Depression, Anxiety and Stress

The Depression Anxiety Stress Scale (DASS-21) [14] in which higher scores indicate more symptoms, strongly correlates with other measures of depression and anxiety, indicating good convergent validity [14]. Good reliability has been reported with Cronbach's alphas ranging from 0.82 for anxiety, 0.90 for stress and 0.93 for the total scale [15, 16]. Comparisons were made with normative data from an Australian population sample of 497 [17].

6.3.2.4 Secondary Traumatic Stress, Compassion Satisfaction and Burnout

The Professional Quality of Life Scale (ProQoL) [7] is a 30-item self-report measure in which higher scores indicate a worse quality of life. The alpha reliability for the compassion satisfaction scale is $r=0.88$ ($n=1130$), the alpha reliability for burnout scale is

$r=0.75$ ($n=976$) and the compassion fatigue scale is $r=0.81$ ($n=1135$) [7]. No Australian normative data has been collected for this measure. Scores on the ProQoL were converted to t -scores to compare the sample data to a data bank of 760 cases, created from multiple studies [7]. Females were selected as a comparison group over males due to the gender bias of the Princess Margaret Hospital sample.

6.3.2.5 Coping Style

The Coping Scale for Adults (CSA) [18] identifies 18 coping strategies categorised into four coping styles: dealing with the problem, optimism (thinking positive), sharing (problem solving with the help of others) and non-productive coping. ‘Dealing with the problem’ is a coping style that:

encompasses working hard and solving the problem while maintaining a social dimension characterized by relaxing and indulging in humorous diversions and physical recreation as well as attempting to improve the significant relationships in one’s life. It also includes the use of techniques which aim to enhance the maintenance of self-esteem [18].

Non-productive coping involves strategies such as, ‘worry, keep to self, self-blame, wishful thinking, ignore the problem and tension reduction’ [18]. Higher scores indicate greater use of coping strategies. The CSA has good psychometric properties with internal consistency ranging from $\alpha=.69$ to $.92$ [18]. Normative data of a sample of 371 Australian adults was used as comparison [18].

Additional information collected by a self-administered questionnaire included gender, age, ethnicity, occupation, duration of service at Princess Margaret Hospital, troubles experienced at work and whether a mental illness had ever been diagnosed.

6.3.2.6 Data Analysis

Visual inspection of histograms and Shapiro-Wilk and Kolmogorov-Smirnov tests confirmed that none of the outcome variables (except resilience and compassion satisfaction) were normally distributed. For this reason, the data were described with non-parametric statistics. However, the study was restricted to using parametric statistics (t -tests) when comparing our data to previously published control data, since most articles

do not report median values. Cohen's d (effect size) was reported for the t -tests to indicate the magnitude of the difference between sample mean and population mean. The H statistic, computed from the Kruskal-Wallis one-way ANOVA ranked test corrected for ties examined the significance of differences between outcome variables in groups defined by pre-existing factors such as age, occupation and length of employment.

This is an exploratory, descriptive study and found a clear break between those aged less than 25 years old and those who were at least 25 years old. This point is also described in the literature as the turning age where individuals begin to establish a career for themselves and was deemed appropriate to divide the sample into such age groupings [5]. Spearman's rho estimated correlations between outcome variables. A p value <0.05 was considered statistically significant. All analyses were performed using SPSS version 19.

6.4 Results

The majority of participants (72.7 per cent) were born in Australia and 40.7 per cent were married. The mean length of employment at Princess Margaret Hospital was five years and 74.1 per cent worked full-time. Four health professionals reported a previously diagnosed mental illness. The majority of the participants were female (83.3 per cent), which is representative of the work force at Princess Margaret Hospital (see Table 6.1).

Table 6.1: Sample Demographics Distribution of Gender, Age and Occupation

Sample descriptor	<i>n</i>	%
Gender		
Female	45	83.3
Male	9	16.7
Age		
Less than 25	8	14.8
25–34	22	40.7
35–44	11	20.4
45–54	12	22.2
55–64	1	1.9
Occupation		
Doctor	6	11.1
Nurse	23	42.6
Occupational therapist	6	11.1
Physiotherapist	3	5.6
Social worker	2	3.7
Speech pathologist	2	3.7
Pharmacist	1	1.9
Play co-ordinator	4	7.4
Teacher	2	3.7
Therapy assistant	2	3.7
Ward clerks	3	5.6

The mean scores for PTSD, intrusion and avoidance were slightly, but not significantly, lower than US population means (see Table 6.2). The mean score for depression was slightly, but not significantly lower than Australian population mean scores and there was no difference between mean scores for anxiety. Twenty-one per cent of the sample experienced above average symptoms of depression, of whom 11 per cent experienced mild symptoms, six per cent moderate symptoms and four per cent severe symptoms. Above average symptoms of anxiety were reported by 17 per cent of the sample, of whom four per cent experienced mild symptoms, seven per cent moderate symptoms and six per cent severe symptoms. Nineteen per cent of the sample experienced above average symptoms of stress, of whom seven per cent reported mild symptoms of stress, six per cent reported moderate symptoms and six per cent reported severe symptoms.

Compared with population means, participants demonstrated statistically significant greater symptoms of STS, lower resilience, greater use of optimism and sharing and less

use of ‘dealing with the problem’ and non-productive coping. The participants also demonstrated statistically significant less compassion satisfaction and had slightly, but not statistically significant, more symptoms of burnout (see Table 6.2).

Table 6.2: Outcomes Compared to Population Reference Groups

Variable	Sample <i>M(SD)</i>	Reference group <i>M(SD)</i>	Mean Difference[CI]	<i>d</i> *	<i>p</i>
PTSD	7.43 (7.12)	8.10 (12.3) ¹²	-0.67 [-2.67, 1.33]	-0.05	0.50
Intrusion	3.23 (3.35)	3.9 (6.2) ¹²	-0.68 [-1.63, 0.26]	-0.11	0.15
Avoidance	3.78 (3.79)	4.2 (6.8) ¹²	-0.41 [-1.48, 0.65]	-0.06	0.44
Hyperarousal	0.30 (0.47)	Not available			
Resilience	74.57 (12.35)	80.4(12.8) ⁹	-5.83 [-9.23, -2.42]	-0.46	<0.01
Depression	2.12 (2.94)	2.21 (3.60) ¹⁴	-0.09 [-0.91, 0.72]	-0.02	0.82
Anxiety	1.48 (2.55)	1.48(2.60) ¹⁴	0.00 [-0.70, 0.70]	0.00	1.00
Stress	3.94 (3.93)	3.79 (4.10) ¹⁴	0.15 [-0.93, 1.24]	0.04	0.78
Compassion satisfaction	39.72 (06.01)	50.14 (9.77) ⁷	10.42 [-12.10, - 8.72]	1.07	<0.01
STS	58.59 (6.88)	50.18 (10.15) ⁷	8.41 [6.47,10.34]	0.83	<0.01
Burnout	51.02 (6.94)	50.37 (10.26) ⁷	0.65 [-1.28, 2.58]	0.06	0.50
Dealing with the problem	66.83 (10.09)	92.38 (14.31) ¹⁵	-25.55 [-28.4,-22.6]	-1.79	<0.01
Optimism	52.01(9.58)	41.39 (8.06) ¹⁵	10.63 [7.99, 13.27]	1.32	<0.01
Sharing	50.72 (19.83)	27.82 (7.52) ¹⁵	22.90 [17.38, 28.42]	3.04	<0.01
Non-productive	46.30 (10.51)	66.04 (15.73) ¹⁵	-19.74 [-22.62,- 16.84]	-1.25	<0.01

[12, 9, 14, 7. 15] * Cohen’s *d* (effect size) was reported for the *t*-tests to indicate the magnitude of the difference between sample mean and population mean.

6.4.1 Pre-existing Factors, Psychological Distress, Resilience and Coping Strategies

Symptoms for health professionals aged 25 to 64 did not vary greatly with age, but differed from those aged less than 25 years (see Table 6.3). Health professionals under the age of 25 years demonstrated higher mean and median symptoms of PTSD, depression, anxiety, stress, burnout and STS, and lower resilience and compassion satisfaction than those aged 25 to 64. They were also significantly more likely to use non-productive coping strategies ($p=0.05$), less likely to share ($p=0.05$), and had a tendency towards more

symptoms of depression ($p=0.06$). No other significant differences in outcome measures were found between groups defined by gender, occupation or length of employment.

	PTSD	PTSD	Resilience	Resilience	Depression	Depression	Anxiety	Anxiety	Stress	Stress	Compassion satisfaction	Compassion satisfaction
Age	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs
<i>N</i>	6	44	8	45	7	45	8	46	8	45	7	44
Mean (SD)	2.49 (1.63)	1.13 (1.28)	65.25 (18.01)	76.22 (10.50)	6.86 (5.27)	3.82 (5.92)	3.75 (5.99)	2.83 (4.99)	10.25 (8.64)	7.45 (7.74)	36.86 (8.53)	40.14 (5.50)
Median	3.08	0.63	67	76	6	2	2	0	10	4	39	41
Range	0–3.92	0–5.42	41–91	56–96	0–14	0–24	0–18	0–18	0–26	0–28	24–50	29–50

Table 6.3: Outcomes by Age <25 and ≥25 years

	STS	STS	Burnout	Burnout	Dealing with the problem	Dealing with the problem	Non-productive	Non-productive	Optimism	Optimism
Age	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs	<25 yrs	25–64 yrs
<i>N</i>	7	44	7	44	7	43	7	46	7	46
Mean (SD)	20.71 (5.88)	17.50 (4.20)	23.43 (5.77)	21.00 (4.80)	61.45 (11.76)	67.70 (9.66)	53.33 (12.73)	45.23 (9.86)	48.79 (13.01)	52.51 (9.04)
Median	18	16	23	22	66.14	68.43	56	43.64	50.75	51.12
Range	14–29	11–27	16–33	12–31	42–72.86	48.43–84.00	27.86–65.14	28.43–69.86	34–70.75	35.25–77
	Sharing	Sharing								
Age	<25 yrs	25–64 yrs								
<i>N</i>	7	45								
Mean (SD)	35.36 (23.52)	53.11 (18.36)								
Median	32.50	52.50								
Range	7.50–75.00	10–105								

* This is an exploratory, descriptive study and we found a clear break between those aged less than 25 years old and those who at least 25 years old. This point is also described in the literature as the turning age where individuals begin to establish a career for themselves.

Staff who reported difficulties at work with their superior, a colleague or a colleague under their supervision demonstrated significantly lower levels of resilience ($p=0.037$) and higher levels of stress ($p=0.031$), than staff who did not report conflict at work.

There were significant positive correlations between PTSD, depression, anxiety, stress, burnout and STS that were particularly strong for symptoms of stress and symptoms of both depression and anxiety (see Table 6.4). There was also a moderately strong correlation between compassion satisfaction and resilience. As anticipated, both these factors were negatively correlated with all other outcome measures.

Table 6.4: Correlations (Spearman's Rho) Between Outcome Variables

	Resilience	PTSD	Depression	Anxiety	Stress	Burnout	STS	Compassion satisfaction
Resilience	1.000							
PTSD	-.356*	1.000						
Depression	-.507**	.608**	1.000					
Anxiety	-.445**	.362**	.546**	1.000				
Stress	-.500**	.518**	.773**	.719**	1.000			
Burnout	-.649**	.483**	.591**	.469**	.576**	1.000		
STS	-.441**	.461**	.390**	.437**	.437**	.597**	1.000	
Compassion satisfaction	.426**	-.048	-.201	-.244	-.123	-.533**	-.284*	1.000

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

Non-productive coping strategies were positively correlated with all adverse psychological outcomes and negatively associated with both resilience and (non-significantly) with compassion satisfaction (see Table 6.5). However, the three positive coping strategies were not significantly negatively correlated with adverse psychological

outcomes, the exception being burnout with optimism. Of the positive coping strategies, dealing with the problem was significantly positively correlated with compassion satisfaction and optimism was associated with resilience.

Table 6.5: Correlations Between Coping Strategies and Psychological Factors

	Resilience	PTSD	Depression	Anxiety	Stress	Burnout	STS	Compassion satisfaction
Dealing with the problem	.220	.238	-.185	.099	.410	-.170	.169	.300*
Optimism	.482**	-.091	-.179	-.122	-.231	-.370**	-.046	.172
Sharing	.119	-.064	-.236	-.065	-.022	-.082	.042	.260
Non-productive	-.322*	.411**	.542**	.417**	.519**	.453**	.504**	-.210

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed)

Dealing with the problem was significantly associated with both optimism and sharing. Non-productive coping showed little association with the three positive strategies (see Table 6.6).

Table 6.6. Correlations Between Coping Strategies

	Dealing with the problem	Optimism	Sharing	Non-productive coping
Dealing with the problem	1.000			
Optimism	.394**	1.000		
Sharing	.421**	.136	1.000	
Non-productive coping	.096.	-.124	-.174	1.000

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

The only significant or clinically meaningful relationships between demographic variables and psychological factors are shown in Table 6.7. With increasing length of employment (and age), health professionals were more likely to share their problems and deal with them productively, less likely to have symptoms of anxiety or use non-productive coping strategies and reported greater compassion satisfaction.

Table 6.7: Linear Correlations Between Demographic Variables and Psychological Factors

	Dealing with the problem	Non- productive coping	Sharing	Anxiety	Compassion satisfaction
Age	.295*	-.192	.320*	-.224	.294*
Length of employment	.333*	-.284**	.483**	-.280*	.348*

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

6.5 Discussion

In relation to Hypothesis (a), no significant differences were identified between levels of PTSD, depression, anxiety and stress when comparing health professionals with the general population. However, cumulative exposure to paediatric medical trauma places health professionals at risk of developing more symptoms of STS and burnout, while having less resilience and compassion satisfaction than general population samples. These findings are consistent with previous studies reporting the impact of trauma exposure on various healthcare professionals [5, 19–21]. Acknowledging the impact of paediatric medical trauma on health professionals' mental health is an important step towards maintaining a healthy workforce.

To test Hypothesis (b), this study compared health professionals aged 25 years or above with health professionals aged below 25. Those aged less than 25 years experienced more symptoms of PTSD, depression, anxiety, stress, burnout and STS and had less compassion satisfaction, used more non-productive and sharing coping strategies and

demonstrated lower levels of resilience. These results indicate that young health professionals are vulnerable to experiencing significant distress and interventions are required to support them. Supporting health professionals as they transition from university into clinical practice may be an important timepoint for occupational assistance.

Further longitudinal research is required to determine if young health professionals leave the profession after experiencing distress so that only the most resilient remain, or if they acquire more productive coping skills as they mature and learn to adjust to the work environment. High staff turnover rates may suggest the former, in which case, more investigation is required to understand this complex and poorly researched area of occupational hazard.

In contrast to US findings [5], length of employment had a moderate, significant and positive relationship with productive coping strategies and compassion satisfaction. The US findings suggest a model of cumulative stress, in which continued exposure to trauma over time is associated with increasing symptoms of distress [5, 22]. Results from this study support recent research suggesting that cumulative traumatic exposure can instead lead to vicarious post-traumatic growth [23, 24], with empathy found to be a predictor of growth [23].

A component of compassion satisfaction is a health professional's ability to empathise with patients and findings from this study show a moderate, positive relationship between length of employment and compassion satisfaction. A randomised controlled trial found that it is possible to teach physicians effective empathy skills [8]. The practice of empathy was found to be associated with improvements in patient satisfaction [25], reductions in medical errors [26] and malpractice claims [25], suggesting that it is important skill to teach all health professionals.

Individuals who experienced difficulties at work, including difficulties with their superiors and colleagues demonstrated significantly less resilience and more stress. These findings support research reporting increased symptoms of emotional exhaustion and depersonalisation in nurses who experience negative perceptions of their environment and decreased supervisor support [27]. The current research findings may provide new

evidence and direction for paediatric health services when reviewing practices to improve staff wellbeing and function.

In relation to Hypothesis (c), non-productive coping was associated with significantly higher levels of STS, burnout, PTSD, anxiety, depression and stress, while resilience was associated with positive coping strategies, particularly optimism. The findings suggest that coping strategies had a greater influence on health professionals' psychological profiles than pre-existing factors such as gender, occupation and length of time employed at Princess Margaret Hospital. In this study, health professionals used 'dealing with the problem' as a coping strategy significantly less than the general population. The results suggest staff are less willing to problem-solve or resolve conflicts as a first point of action. These results are consistent with research conducted in the US suggesting that paediatric health professionals who use more effective self-care coping strategies have lower stress levels [19]. In a qualitative research sample of twenty paediatric nurses, coping strategies such as exercise, meditation and journaling were reported to be critical in managing symptoms of burnout and compassion fatigue [28]. To prevent the development of STS, burnout, PTSD, anxiety, depression and stress in health professionals, it is imperative that effective interventions are recommended.

6.5.1 Strengths and Limitations

The high response fraction (approximately 80 per cent) provided an accurate representation of the two medical departments. A control group was not utilised in this design, limiting the ability to draw definite conclusions regarding the impact of paediatric medical trauma. However, this effect was minimised by selecting outcome measures with normative data available. It should be noted that Australian normative data was not always available, in which case US data was used, which may limit the validity of the comparisons. The cross-sectional design means that conclusions cannot be drawn about the causal direction of identified relationships, highlighting the need for prospective longitudinal research. Additionally, small numbers in sub-groups, such as those <25 years old suggest findings should be interpreted cautiously, and further research with larger numbers is required.

This was an exploratory study that aimed to describe the experience of health professionals exposed to paediatric trauma. Despite recruiting all available willing participants, this study is underpowered for many desirable subgroup analyses. However, being the first such study in Australia, any associations that may be useful in promoting psychological resilience in paediatric health professionals exposed to trauma are considered worth identifying. Therefore, this study considers that falsely rejecting possible associations a lesser evil compared to accepting false associations, in which case, setting statistical significance at the traditional value of $p < 0.05$ (i.e. a five per cent likelihood that the association arose as a result of chance sample selection) must be considered conservative and correction for multiple comparisons is not appropriate. Some of these associations may be the result of chance sample selection, identifying which of these associations are not generalizable must be the subject of research in independent samples. Therefore, all associations are reported to not exclude any associations that may prove clinically useful.

6.6 Conclusion

Findings from the present study highlight that exposure to paediatric medical trauma affects health professionals' wellbeing and mental health, particularly those under 25 years of age and that resilience is associated with the use of positive coping strategies, particularly optimism. The relationships identified in this research may assist in developing organisational systems to facilitate optimal mental health and coping strategies in health professionals, thereby reducing sick leave, absenteeism, early retirement and staff turnover, resulting in the maintenance of a healthy workforce and ameliorating shortages of health professionals in Australia.

6.6.1 Previous Knowledge on this Topic

- Healthcare professionals working with traumatically injured adults are at increased risk of experiencing negative psychological effects.
- Research conducted in paediatric hospitals in the US found staff to be at risk of experiencing compassion fatigue, burnout and STS.
- There is a growing national shortage of healthcare professionals.

6.6.2 Contributions of this Paper

- This paper uses a descriptive, cross-sectional research design to assess prevalence rates and associations between psychological distress, resilience and coping skills in two multidisciplinary teams working in two different high acuity trauma units in a large children's hospital.
- Younger health professionals (aged less than 25years) experienced higher rates of concerning psychological symptoms. They reported less compassion satisfaction and used less functional coping strategies, while demonstrating lower rates of resilience compared to their older and more experienced colleagues.
- The findings demonstrate that the use of functional coping strategies had a greater influence on an individual health professional's psychological wellbeing compared to a variety of other key factors.

6.6.3 Conflict of Interest

No authors have a conflict of interest.

6.7 References

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Chapter 7: Limitations

The qualitative research used one time point for data collection. Additional interviews after the event, during the inpatient and outpatient phase would be of benefit for future studies to gain an expanded understanding of the experience at each stage. Due to the nature of a traumatic event, a randomised control trial or pre- and post-test design was not possible when investigating the impact of paediatric medical trauma on parents and health professionals. This is a difficulty frequently encountered in clinically based research. To minimise the impact of a lack of comparison group, normative data from appropriate general populations in the community (Australia and United States) were used.

The outcome measures in the two quantitative studies were screening tools and indicate symptoms, not diagnoses. Symptoms of PTSD must persist for a minimum of one month for a diagnosis [1] and parents were assessed within one week of the accident. It is acknowledged that it is normal for parents to be distressed after a traumatic event, but it is considered important to screen for symptoms of acute psychological distress to understand the magnitude of distress experienced by parents. Although there is the potential for individuals with a previously diagnosed mental illness to skew the data, it was considered important not to exclude these parents in the desire to capture a sample as close to the clinical population as possible.

Numbers within each subgroup in the quantitative studies were small. These findings provide preliminary evidence for previously unknown risk factors. However, future research with larger numbers in each subgroup would expand on these findings. The cross-sectional design prevents conclusions being drawn about the causal relationships between variables. Longitudinal research is required to describe these relationships.

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Chapter 8: Conclusions and Recommendations

8.1 Overview

This thesis used a multi-factorial approach to investigate the impact of paediatric medical trauma on children, parents and staff within a paediatric hospital. Firstly, the study sought to understand the experience of children hospitalised for a burn. In doing so the study aimed to investigate the lived experience from the point of view of the child and thus identify stressors and functional and behavioural implications.

Secondly, this thesis investigated the impact paediatric medical trauma has on parents of children with burn injuries. In doing so, the thesis aimed to understand relationships between adverse psychological outcomes and resilience in all parents, as well as identifying differences in demographic factors. The third paper explored the lived experience of parents who have a child with a burn injury. Using a qualitative methodology enabled the disclosure of aspects of the parental experience not collected in standardised outcome measures, expanding on the quantitative results found in the second study. The fourth paper investigated the impact of paediatric medical trauma on health professionals. Children, parents and health professionals are interconnected in a professional relationship and the study sought to understand how paediatric medical trauma impacts health professionals' wellbeing and what risk factors lead to poorer health outcomes.

The impact of paediatric medical trauma on children, parents and staff was addressed using four interrelated studies. This chapter will summarise the findings of each of these studies with respect to the hypotheses and research questions developed in Chapter 1, draw conclusions based on the results of each of these studies and make recommendations for clinical practice, knowledge translation and future research.

8.2 Discussion

This research is unique as it investigates three key populations (children, parents and staff) within a paediatric hospital and uses a mixed-methods approach to facilitate multi-factorial investigations. This approach allows the collection of information from multiple perspectives, expanding the depth and breadth of the inquiry [1]. Utilising both qualitative and quantitative research methods ensures a greater understanding of paediatric medical traumatic stress.

The model of paediatric medical traumatic stress underpins the design of this research and provides the theoretical framework [2]. Although this model has been documented in the literature, it has not previously been validated in research [2]. The mixed methods used in this research allow the testing and validation of the model of paediatric medical traumatic stress from multiple perspectives, providing triangulation of data and a rich, in-depth understanding [1, 3].

8.2.1 Pre Existing factors

Findings from the qualitative investigation of parents with children who had sustained a burn provided validation for the model and this thesis is the first study to describe this experience qualitatively. Data revealed that the parental experience reflected a journey represented by three phases: the event, the inpatient phase and the return to the community. This supports the phases outlined by the model of paediatric medical traumatic stress [2]. The present research identifies that the needs of parents change as they progress through the various phases, as do their behavioural responses and coping strategies. These findings expand on the model of paediatric medical traumatic stress, providing a more comprehensive picture of the parental experience of having a child sustain a burn injury.

The present quantitative parental findings also validate and elaborate on the model of paediatric medical trauma. Pre-existing factors can contribute to the perception of an event as traumatic and to the subsequent development of PTSD symptoms [2, 4]. It is known that age (younger), female gender, a history of trauma, psychiatric history and low

pre-morbid social support increase the likelihood of poor psychological adjustment post-trauma [4–11]. Findings from this study confirm that a history of previous trauma significantly influence symptoms of psychological distress and resilience. Although female gender has been reported as a risk factor for adverse psychological outcomes following trauma, in this study, there were no statistical differences identified between mothers and fathers.

While the results showed no statistical differences, a trend was evident regarding parents with lower incomes reporting higher mean scores for anxiety and depression and parents who were unemployed having lower mean scores for resilience. In contrast, there was a trend for employed parents to demonstrate more symptoms of depression, anxiety and stress. Aboriginal parents in our study reported higher mean scores for symptoms of PTSD, depression, anxiety and stress compared to non-Aboriginal parents, although no statistical differences were identified. These findings provide preliminary evidence for previously unknown risk factors. Future research with larger numbers in each subgroup would expand on these findings.

8.2.2 Characteristics of the event

Characteristics of the event known to influence the development of PTSD include perceived life threat during the traumatic event, severity of exposure to the trauma, emotional response during the event, and signs of post-traumatic hyperarousal such as an elevated heart rate [4, 12, 13]. The present results show that factors such as having a daughter, witnessing the burn occur and feeling helpless at the time of the event significantly influence symptoms of psychological distress and levels of resilience in parents of burn survivors. These factors have a greater influence on psychological functioning than objective measures of trauma. No significant differences or trends were found when comparing size, location and mechanism of the burn with psychological distress in parents. These results support the theory that the subjective experience of the event has a greater influence on whether an event is perceived to be traumatic than objective measures of trauma and are of clinical importance for screening families [2].

8.2.3 Phase II: Early and Evolving Responses

Quantitative data collected from parents one week after the event confirm that the acute phase, as outlined by the model of paediatric medical traumatic stress, is characterised by significant psychological distress. Parents in this study experienced significantly more symptoms of PTSD than the comparison population. The findings also show that parents report lower levels of resilience and more symptoms of depression and anxiety than a comparative community population, although there is no statistical difference. These results highlight that the acute phase (one week) post-burn injury is a critical time for health professionals to intervene and support families.

Data from the child qualitative study did not validate the three phases of the model of paediatric traumatic stress because child participants did not describe their experience as a continuum of phases, but as an individual journey. Phenomenology reveals and illuminates general assumptions about an experience, allowing a deeper perceptive and understanding of the essence of the lived experience [14]. Two phases of trauma were central to their burn experience. Children described the first phase (the burn trauma) as the event of sustaining the burn and seeking medical assistance, whereas the second phase (the recovery trauma) involved painful and frightening medical procedures. This research identifies that children experience ongoing trauma in addition to the initial trauma of sustaining the burn, resulting in a cumulative trauma experience.

Although the model of paediatric medical traumatic stress is descriptive in terms of a child or family moving between the phases in a non-linear pattern, the current findings indicate that recurrent trauma frequently occurs during the acute phase for some children, suggesting recurrent movement between Phases I and II. Investigating the child's lived experience using phenomenology enabled a greater understanding of what living with a burn is like from the perspective of the child, a phenomenon that, until now, has not been documented. The data reveals that behavioural and emotional changes in children and within family functioning are present. The current research demonstrates that paediatric medical trauma can affect all aspects of child wellbeing.

Unlike parents and children, health professionals do not usually experience a single, acute traumatic event, but rather an accumulation of traumatic events. This accumulation of

traumatic events can often occur over several years. The model of paediatric medical traumatic stress was not developed to describe the experience of health professionals, yet some similarities are evident in relation to pre-existing factors. This research identifies age as a pre-existing factor that increases a health professional's vulnerability to developing adverse psychological outcomes. Compared with health professionals aged above 25 years, those aged under 25 experience more symptoms of PTSD, depression, anxiety, stress, burnout, STS and have less compassion satisfaction, use more non-productive and sharing coping strategies and demonstrate lower levels of resilience. These results suggest younger age is a risk factor for the development of more psychological distress and negative coping skills in paediatric health professionals. Other pre-existing factors such as gender, occupation or length of employment do not significantly influence the psychological profiles of health professionals in the present study.

Workplace characteristics such as experiencing difficulties with a superior or colleagues significantly influence symptoms of stress and levels of resilience in health professionals. Coping strategies utilised also significantly influenced the psychological profiles of health professionals. The results show that non-productive coping is associated with significantly higher levels of STS, burnout, PTSD, anxiety, depression and stress, while resilience is linked to positive coping strategies, particularly optimism. These results highlight the importance of coping strategies in influencing wellbeing.

The study described in chapter six found that cumulative exposure to paediatric medical trauma places health professionals at risk of developing greater STS and burnout, and less resilience and compassion satisfaction compared to general population samples. However, these findings are not sufficiently conclusive to draw discrepancies between acute responses and long-term responses, as described by the model of paediatric medical traumatic stress. A further, longitudinal study is required.

Health professionals working in paediatric hospitals provide critical medical interventions for children and provide psychological support for parents. Parents are present for the majority of all interactions between health professionals and patients and once discharged, health professionals transfer the responsibility of caring for the child back to the parents. For these reasons, there is a strong professional relationship between the child, the parents and the health professionals. Acknowledging the impact of paediatric medical trauma on

the mental health of health professionals is an important step towards maintaining a healthy workforce, and will lead to improvements in the therapeutic relationship between children, parents and staff.

8.3 Recommendations for Clinical Practice

Findings from this research provide evidence to enable health professionals to optimise a holistic clinical service at all stages of the burn journey. The conclusions drawn from this research could be used to inform the development of protocols to underpin a comprehensive information and social support management plan for families that would complement and support the surgical, medical and allied health treatment plan. The recommendations discussed in this section provide direction for a comprehensive model of service delivery.

One week post-burn is a critical timepoint for health professionals to communicate important information to children and parents regarding the child's health and medical treatments. This research identifies that parents experience significant psychological distress and children do not receive or process information accurately during this period. Provision of information is identified as having a calming effect and seeking out further information is used as a coping strategy by parents. Parents who believed they did not receive adequate information reported feeling anxious, worried and stressed. Symptoms of acute stress during this stage will affect a parent and child's ability to absorb and retain information from health professionals. Therefore, it is important that information is provided in a verbal, written and visual format and that consideration is given to the amount of content provided, as well as the timing of information. Developmental factors such as children's age and cognition should be taken into consideration when developing information packages. Resources such as educational programmes delivered on electronic devices as well as written pamphlets regarding the physiological and psychological process of burn injuries could be provided to complement verbal information.

For children and parents, preparatory information about medical procedures specific to burn care is required. Health professionals can educate parents and children about the procedure to ensure they are aware of what will occur. Explaining medical procedures to

parents and supporting them with techniques to reduce anxiety during these procedures may help to minimise distress [15, 16]. Educating and preparing children and parents by enhancing information provision may minimise the potentially traumatic aspects of medical procedures and diminish distress. However, it is important that the delivery of information is consistent across the multidisciplinary team to minimise confusion for children and parents. Educational resources should be culturally appropriate and accessible for rural patients once discharged into the community.

In addition to preparatory information, pain management during medical procedures, particularly dressing changes, must be addressed. Pain was identified as a significant issue by both parents and children. Comprehensive assessment of pain and the implementation of pharmacological and non-pharmacological methods of pain management are required to minimise subsequent problems associated with pain during invasive and frightening medical procedures.

This research identified new risk factors and validated known risk factors in a sample of parents of burn survivors in Western Australia. Given the emotional, physical and financial cost of mental illness to the Australian community, it would be beneficial to future parental wellbeing to screen parents for risk factors upon their child's admission to hospital. This would allow the provision of supports for families prior to discharge into the community. Screening parents identifies families at greatest risk of experiencing poor psychological adjustment post-trauma and targets service delivery towards those who need it most. Early service provision has the potential to reduce further development of psychological distress, improving health outcomes for families of burn survivors [17].

The results of this study show parental stress as directly correlated with all adverse psychological outcomes and low levels of resilience were associated with increased symptoms of PTSD and stress. To universally influence parental wellbeing, the development of interventions aimed at reducing stress and building resilience is recommended. These therapeutic interventions should be provided to parents as part of standard, routine care.

This constitutes the first study to include the experiences of Aboriginal parents and children who have sustained a burn. The quantitative study found that Aboriginal parents

experienced significant levels of distress. Further, the qualitative data revealed that maintaining close contact with family is extremely important for both Aboriginal parents and children. A key priority outlined in the *National Strategic Framework for Aboriginal and Torres Strait Islander Health* is to ensure the development of a workforce resourced, skilled and supported to address the mental health needs of Aboriginal children and adults [18].

When providing psychological support for Aboriginal people, it is recommended that health professionals recognise existing frameworks of healing present in Indigenous communities and acknowledge that culture and spirituality in relation to social and emotional wellbeing are sources of strength [19]. Traditional Aboriginal healing is holistic and focusses on wellbeing, incorporating an individual's emotional, spiritual, physical and social needs [19]. Aboriginal people view good health as not only the presence of doctors, hospitals and medicines, but also the inclusion of a holistic approach [20].

Terms like 'healing' and 'journey of healing' that encompass Aboriginal spirituality are often preferred [21] and are terms this study recommends for use by health professionals when discussing the burn journey with Aboriginal children and parents. *The National Strategic Framework for Aboriginal and Torres Strait Islander People's Mental Health and Social and Emotional Wellbeing (2004–2009)* contains nine guiding principles that health professionals can use to ensure they undertake culturally sensitive practice at each stage of intervention of the model of paediatric medical traumatic stress. All health professionals working within paediatric hospitals have access to an Aboriginal health worker, and it is recommended health professionals utilise this service [18]. It is recommended that health professionals work with Aboriginal parents and children to develop therapeutic tools that are culturally acceptable and appropriate, leading to a holistic and culturally sensitive delivery of services.

A key issue outlined in *Primary Health Care Reform* in Australia [22] was that improvements be made to ensure continuity of care is supported for all Australians. This includes the application of primary healthcare services that are coordinated across multiple care providers, and transitions across health sectors are to be actively managed [22]. Supporting parents as they make the transition from hospital to community is

important, especially for parents living in rural areas [23]. This research found that families find this time difficult and stressful. More emphasis should be placed on communication for discharge planning to ensure parents are confident in managing their child's injury after leaving the inpatient unit [24]. Ensuring parents are well resourced is important for continuity of care and transition of services, thus meeting the patient's needs across the broad continuum of care.

This research found that both children and parents wish to be better informed and involved in all stages of care. It is recommended that treatment planning be guided by an ecological framework and be family-centred. In a family-centred approach, the multidisciplinary team is directed by the priorities of the family [25] and goal setting should be directed by children and their parents. This family-centred, goal-directed approach to treatment planning, intervention and evaluation encompasses evidence-based best practice and underpins culturally sensitive practice [25]. This approach ensures that all treatment plans are flexible, and recognises each family's unique environmental and cultural context [25].

This research provides new evidence and direction for paediatric health services to improve staff wellbeing. Findings from this study suggest staff experience significant psychological distress, particularly young health professionals. Coping strategies were shown to have a greater influence on health professionals' psychological profiles than pre-existing factors such as gender, occupation and length of time employed at a paediatric hospital. For this reason, the development and implementation of interventions aimed at educating staff about effective coping strategies and self-care techniques are recommended. Given young health professionals are at higher risk for developing more symptoms of psychological distress, it is recommended that supports are developed to facilitate the transition from university into clinical practice. This could be undertaken in the form of education and supervision during practical placements prior to graduation. Senior health professionals have an important role in mentoring and supervising new graduates. It is recommended they provide adequate supervision for new graduates and regular education on effective coping strategies and signs of stress. To improve the wellbeing of paediatric health professionals, it is imperative that effective interventions are developed, implemented and evaluated.

8.4 Knowledge Translation

New knowledge does not always lead to widespread implementation [26]. Knowledge must be translated into changes in practice and policy for the benefits to flow to individuals [26, 27]. However, research suggests that less than half of evidence-based practices are implemented into clinical practice and that, on average, it takes 20 years for research-generated knowledge to be implemented into clinical practice [28, 29]. Therefore, to provide insight and practical direction for implementing evidence-based improvements in burns care, the process of knowledge translation must be performed [27]. The Ottawa model of research use guides the successful implementation of knowledge translation into clinical practice and policy [30]. The model follows a three phase approach to guide the implementation of new knowledge [30]. The three phases consist of assessing barriers and supports; monitoring the intervention and degree of use and finally evaluating the outcomes [30]. Throughout the progress of this research project, the first phase of knowledge translation has been completed and the first three key points from this model have been covered: evidence-based innovation, potential adopters and the practice environment.

This research was underpinned by a theoretical evidence-based framework and was designed with input from a multidisciplinary team enhancing the applicability of the research. Potential adopters of change to clinical practice in this study are healthcare professionals. To overcome possible barriers that may impede translation to clinical practice, the researcher facilitated formal and informal lines of communication with health professionals (potential adopters). This included meetings with management teams from several medical and allied health departments, as well as conducting information sessions on wards with health professionals. Communication platforms were conducted during the design and data collection stage of this research and involved gaining a sense of the concerns and attitudes of health professionals, as well as enhancing awareness, knowledge and attitudes within the cultural context of the practice environment.

An identified strength of this project is evident in that the research was undertaken within the practice environment. In conducting research in the practice environment, the researcher was able to interact with health professionals and patients, accelerating the

synthesis of knowledge. Once research is conducted, dissemination of findings to key stakeholders is pivotal in the translational process [26]. Dissemination of findings from this research was conducted within the practice environment via presentations to health professionals, management teams and policy makers.

To extend the applicability of these findings to other environments, knowledge generated from this study was disseminated internationally and nationally. This has been conducted in the form of several conference presentations and an educational webinar for Australian health professionals will be conducted later this year. In addition to oral presentations, dissemination has been performed in a written context with two papers published in peer-reviewed journals, both of which reach a broad clinical audience.

Engaging key stakeholders including patient consumer groups enables the translation of knowledge into clinical practice and policy to be consumer-driven and to continually expand to meet the changing needs of the consumers. The researcher has begun to disseminate findings to consumers involved in this research, also engaging with the public via publishing information in public forums, such as a not-for-profit organisation aimed at enhancing the wellbeing of burns survivors.

Throughout the process of this research project, the researcher has engaged with stakeholders in an Aboriginal health service located in rural Western Australian. The research findings have a broad applicability to many environments and it is important steps be made to translate this knowledge to all relevant stakeholders.

Disseminating knowledge and engaging with policy makers is a key step towards translating new knowledge identified from this study. This could be undertaken via the National Lead Clinicians Group. This group provides direct advice to the Minister of Health on prioritising the development and implementation of national clinical standards and guidelines [31]. This would support the development of standard universal procedures ensuring trauma informed care be considered in all paediatric hospitals.

Proposed changes to clinical practice that are cost effective and do not require highly specialised training to administer are more successfully translated into clinical practice [32]. Recommendations for clinical practice that have arisen from the present research can

be implemented by all health professionals within a multidisciplinary team and do not require specialised training. Additionally, these recommendations can be implemented at no added cost to health departments. This is an example of an evidence-based intervention that is feasible and easily implemented.

8.5 Recommendations for Future Research

Investigating the effectiveness of therapeutic interventions aimed at minimising psychological distress in children and parents as a result of exposure to paediatric medical trauma would be of benefit. Of particular importance, research investigating the effectiveness of different methods of providing preparatory information prior to medical procedures and effective pain management strategies should be investigated.

Research should aim to investigate cultural differences among burn survivors and their parents. Identifying differences in culture would lead to the development of more culturally sensitive and appropriate therapeutic interventions for families. In particular, qualitative research using ethnography as a methodology would provide insights into the meaning of culture within the burn journey. This methodology would provide a greater understanding of the experiences of Aboriginal children and families, an important direction for research in Australia. With increasing numbers of refugees requiring treatment for burns and scars, ethnography would provide insights into culturally meaningful therapeutic interventions.

Research involving more objective measures of stress, such as cortisol levels and heart rate in the acute phase would provide concrete evidence and a more in-depth understanding of the physiological impact of paediatric medical trauma on burns survivors. Further, longitudinal research investigating long-term effects of paediatric medical trauma on children and parents is required. Longitudinal studies are required to research functional outcomes in areas such as school and family functioning. Research exploring the link between high levels of stress in children and implications on the nervous system and long-term healing and scarring outcomes would be of future interest.

Research expanding on the results of this study investigating the wellbeing of health professionals is required. Further longitudinal research is required to determine if young health professionals leave the profession after experiencing distress so that only the most resilient remain, or if they acquire more productive coping skills as they mature and learn to adjust to the work environment. Interventions and education programmes should be evaluated for effectiveness; this would require evaluation in the early stage of a health professional's career, as well as combining longitudinal data to determine if interventions are effective in maintaining a healthy work force. With an increased understanding of the psychological impact burn injuries have on children, their parents and the health professionals caring from them, it will be possible to confidently direct service delivery to minimise the psychological impact these injuries can have on the lives of many individuals.

“Being discharged is just the beginning of a longer journey” – Father of a 14 year old
burn survivor

8.6 References

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Appendix B: Ethics Approval



Dear Professor Elliott

REGISTRATION NUMBER: 1855/EP

TITLE: The impact of paediatric medical traumatic stress on children, parents and staff in Princess Margaret Hospital

MEETING DATE: 17 February 2011

RGO and Ethics requirements satisfied 22 March 2011

The Princess Margaret Hospital for Children Ethics Committee and the Research Governance Office consider that the study protocol conforms to the requirements of the NHMRC *Statement on Ethical Conduct in Human Research (National Statement)* and resolved at the meeting to recommend the protocol for approval to the Chief Executive. This recommendation has been ratified by the Child and Adolescent Health Service.

The Ethics Committee does however wish to be informed immediately of:

- I. any untoward effects experienced by any participant in the trial where those effects in degree or nature were not anticipated by the researchers, and steps taken to deal with these,
- II. substantial changes in the research protocol together with an indication of ethical implications, and
- III. other unforeseen events.

The Ethics Committee has been charged with the responsibility of keeping the progress of all approved research under surveillance. A copy of the final result must be forwarded to the Committee upon completion of the research or if the research is not completed within twelve months you are asked to submit a progress report and annually thereafter. This information should include:

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- a) The status of the project (completed/in progress/abandoned/not commenced). In the event that a project does not commence within 12 months of being approved by the Ethics Committee the study must be resubmitted to the Committee for approval.
- b) Compliance with conditions of ethical approval, including security of records and procedures for consent.
- c) Compliance with any special conditions stated by the Ethics Committee as a condition of approval.
- d) Results from the study to date, including outcome.

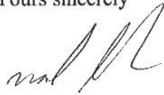
Please note that approval for studies is for **three years** and if the research is not completed within that period of time, a request for an extension of time should be submitted for consideration. In the event that a project does not commence within **12 months** of being approved by the Ethics Committee, the study must be resubmitted to the Committee for approval.

In accordance with the NHMRC National Statement on Ethical Conduct in Human Research Chapter 5.5.3, researchers have a significant responsibility in monitoring and must submit the following to the Ethics Committee:

- Annual Reports on the anniversary of the approval date of the study
- Adverse event reports as received
- Amendments and extensions to the study to be requested in adequate time

Please quote the above registration number on all correspondence.

Yours sincerely



Dr Mark Salmon
Executive Director
Medical Services

22 March 2011

- The Ethics Committee is constituted, and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans

Appendix C: Child Qualitative Letter



CHILD AND ADOLESCENT INFORMATION SHEET Paediatric Trauma: The Impact on Children, Parents and Staff

Why are we doing the study

We are doing this study to look at how an injury can affect the emotions of children, adolescents and their families.

Who is carrying out the study?

- Princess Margaret Hospital (PMH)
- Edith Cowan University (ECU)
- Sarah McGarry is an occupational therapist and is doing her PhD.
- Sarah will be able to help you with the questionnaires

What will the study tell us?

- Findings from this study will provide information and a greater understanding of the impact of trauma on young people.
- The findings may also lead to an improvement in the way in which treatments are delivered.

Do you have to take part?

Participation in the study is voluntary and you may stop at any time or refuse to answer any of the questions. Refusing participation or stopping participation from the study will not affect the treatment you receive from PMH.

What will you be asked to do if you decide to take part in this study?

- You will have an interview with the researcher where you may spend up to two hours talking to each other.
- The interviews will most likely take place at PMH.
- Questions will be asked about what emotional and physical changes you have experienced since your injury. You will not be made to answer any questions that make you feel uncomfortable.
- Six months after you completed the first interview you will be asked to complete the interview again.

What do you have to do to be in the study?

- Be between 3 and 16 years old

- Have had surgery for a burn or have a severe traumatic brain injury
- Be willing to participate.

Is there likely to be any benefit to participating in the study?

Early identification of stress symptoms may decrease the negative feelings you experience over time.

Is there likely to be any benefit to other people in the future?

- Findings from this study will provide information and a greater understanding of the experience of young people who have had an injury.
- This will improve the way people receive services and provide direction for future studies.
- The findings may also lead to changes in the way treatments are delivered, which will improve the health and quality of life (happiness) of young people who have experienced an injury.

What are the possible risks and/ or side effects?

- There are no significant risks to participation
- The study involves answering questions about your feelings and emotions since the injury.
- If you do become upset during the process or require follow up support, this will be provided through PMH.

What are the possible discomforts and/ or inconveniences?

The time required to complete the interview (two hours) may be difficult for you.

Where is your information kept?

- Data will be stored on the researcher's password-protected computer which will be stored in a locked cupboard when not in use.
- Collected data will be retained for five years after the completion of the study in a locked filing cabinet in PMH.

What about my privacy?

Your name will be taken off all the data so that no one knows who you are. This will ensure that no one at the hospital knows what you wrote.

Who has approved the study?

PMH Human Ethics Committee and the Human Research Ethics Committee from ECU have approved this research.

Who to contact for more information about this study?

If you would like any more information about this study, please do not hesitate to contact a member of the research team listed below, they are very happy to answer your questions.

Who to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: (08) 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

THANK YOU FOR YOUR TIME

Sarah McGarry

Occupational Therapist and PhD Candidate

Sarah.mcgarry@health.wa.gov.au

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Associate Professor Jane Valentine

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Rehabilitation

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Appendix D: Parent Qualitative Letter



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service

PARENT / CARE GIVER INFORMATION SHEET

Paediatric Trauma: The Impact on Children, Parents and Staff

Why are we doing the study?

Paediatric traumatic stress refers to the responses experienced by children and their families as a result of an injury. This stress can impact on child and family functioning as well as quality of life. For these reasons Princess Margaret Hospital (PMH) aims to investigate the impact of paediatric traumatic stress on children and parents.

Who is carrying out the study?

This is a collaborative research project between Princess Margaret Hospital (Department of Paediatric Rehabilitation and Burns) and Edith Cowan University (ECU). Sarah McGarry is an occupational therapist and PhD Candidate at PMH. Sarah will conduct this research project alongside a team of researchers and health professionals.

What will the study tell us?

It is anticipated that the findings from this study will provide information and a greater understanding of the impact of trauma on children and families who have experienced a traumatic injury. The findings may also lead to an improvement in the way in which treatments are delivered.

Do you have to take part?

Participation in the study is voluntary and you may withdraw at any time or refuse to answer any of the questions. Refusing participation or withdrawing from the study will not affect the services your child receives from PMH.

What will you be asked to do if you decide to take part in this study?

If you agree to participate in this research you will participate in an interview with the researcher. The interview will take no longer than two hours at the maximum and will most likely take place at PMH. Questions will be asked about what emotional changes you have experienced since your child's injury. You will not be made to answer any questions that make you feel uncomfortable. Six months after you completed the first interview you will be asked to complete a follow up interview.

What do you have to do to be in the study?

Be a primary carer of a child participant and be willing to participate.

Is there likely to be any benefit to participating in the study?

Early identification of psychological distress may lead to improved quality of life.

Is there likely to be any benefit to other people in the future?

It is anticipated that the findings from this study will provide information and a greater understanding of the experience of children and families who have been involved in a potentially traumatic injury. This will improve the way people receive services and provide direction for future studies. The findings may also lead to an improvement or change in the way in which services are delivered, which will ultimately improve the functioning and quality of life of young people who have experienced a traumatic injury.

What are the possible risks and/ or side effects?

There are no significant risks to participation; however the study involves answering questions about your feelings and emotions since the potentially traumatic injury. If you do become upset during the interview or require follow up support, this will be provided through PMH.

What are the possible discomforts and/ or inconveniences?

The time required to complete the interviews may be an inconvenience for you.

Where is your information kept?

Data collected will be de-identified and stored on the researcher's password-protected computer which will be stored in a locked cupboard when not in use. Collected data will be retained for five years after the completion of the study in a locked filing cabinet in the Department of Paediatric Rehabilitation.

What about my privacy?

Your name will be removed from data collected to ensure your confidentiality is upheld at all times.

Who has approved the study?

PMH Human Ethics Committee and the Human Research Ethics Committee from ECU have approved this research.

Who to contact for more information about this study?

If you would like any more information about this study, please do not hesitate to contact a member of the research team listed below, they are very happy to answer your questions.

Who to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: (08) 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

What to do next if you would like your child to take part in this research:

If you would like to take part in this research study, please read and sign the consent form provided.

THANK YOU FOR YOUR TIME

Sarah McGarry
Occupational Therapist
PhD Candidate – Department of Paediatric Rehabilitation
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(08) 9340 8886

Associate Professor Jane Valentine
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Appendix E: Parent Quantitative Letter



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service

PARENT / CARE GIVER INFORMATION SHEET

Paediatric Trauma: The Impact on Children, Parents and Staff

Why are we doing the study?

Paediatric traumatic stress refers to the responses experienced by children and their families as a result of an injury. This stress can impact on child and family functioning as well as quality of life. For these reasons Princess Margaret Hospital (PMH) aims to investigate the impact of paediatric traumatic stress on children and parents.

Who is carrying out the study?

This is a collaborative research project between Princess Margaret Hospital (Department of Paediatric Rehabilitation and Burns) and Edith Cowan University (ECU). Sarah McGarry is an occupational therapist and PhD Candidate at PMH. Sarah will conduct this research project alongside a team of researchers and health professionals.

What will the study tell us?

It is anticipated that the findings from this study will provide information and a greater understanding of the impact of trauma on children and families who have experienced a traumatic injury. The findings may also lead to an improvement in the way in which treatments are delivered.

Do you have to take part?

Participation in the study is voluntary and you may withdraw at any time or refuse to answer any of the questions. Refusing participation or withdrawing from the study will not affect the services your child receives from PMH.

What will you be asked to do if you decide to take part in this study?

If you agree to participate in this research you will complete a series of questionnaires with the researcher. The questionnaires will take no longer than one hour and will most likely take place at PMH. Questions will be asked about what emotional changes you have experienced since your child's injury. You will not be made to answer any questions that make you feel uncomfortable. Six months after you completed the first series of questionnaires you will be asked to complete the questionnaires again.

What do you have to do to be in the study?

Be the primary carer of a child participant and be willing to participate.

Is there likely to be any benefit to participating in the study?

Early identification of psychological distress may lead to improved quality of life.

Is there likely to be any benefit to other people in the future?

It is anticipated that the findings from this study will provide information and a greater understanding of the experience of children and families who have been involved in a potentially traumatic injury. This will improve the way people receive services and provide direction for future studies. The findings may also lead to an improvement or change in the way in which services are delivered, which will ultimately improve the functioning and quality of life of young people and families who have experienced a traumatic injury.

What are the possible risks and/ or side effects?

There are no significant risks to participation; however the study involves answering questions about your feelings and emotions since the potentially traumatic injury. If you do become upset during the interview or require follow up support, this will be provided through PMH.

What are the possible discomforts and/ or inconveniences?

The time required to complete the questionnaires (one hour) may be an inconvenience for you.

Where is your information kept?

Data collected will be stored on the researcher's password-protected computer which will be stored in a locked cupboard when not in use. Collected data will be retained for five years after the completion of the study in a locked filing cabinet in the Department of Paediatric Rehabilitation (PMH).

What about my privacy?

Any identifying features of your data will be removed. Your confidentiality is upheld at all times.

Who has approved the study?

PMH Human Ethics Committee and the Human Research Ethics Committee from ECU have approved this research.

Who to contact for more information about this study?

If you would like any more information about this study, please do not hesitate to contact a member of the research team listed below, they are very happy to answer your questions.

Who to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: (08) 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

What to do next if you would like your child to take part in this research:

If you would like to take part in this research study, please read and sign the consent form provided.

THANK YOU FOR YOUR TIME

Sarah McGarry
Occupational Therapist
PhD Candidate – Department of Paediatric Rehabilitation
Sarah.mcgarry@health.wa.gov.au
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Associate Professor Jane Valentine
Head of Department Paediatric Rehabilitation
Jane.Valentine@health.wa.gov.au

Associate Professor Catherine Elliott
Department Paediatric Rehabilitation
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Appendix F: Staff Quantitative Letter



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service

STAFF INFORMATION SHEET

Paediatric Trauma: The Impact on Children, Parents and Staff

Why are we doing the study?

Paediatric traumatic stress refers to the responses experienced by children and their families as a result of a potentially traumatic injury. This stress can impact on child and family functioning as well as quality of life. Healthcare professionals working within hospitals are indirectly and directly exposed to trauma on a daily basis. Regular exposure to trauma has the potential to effect healthcare workers both negatively and positively. For these reasons Princess Margaret Hospital (PMH) aims to investigate the impact of paediatric traumatic stress on children and parents and staff.

Who is carrying out the study?

This is a collaborative research project between PMH and Edith Cowan University (ECU). Sarah McGarry is an occupational therapist and PhD Candidate at PMH. Sarah will conduct this research project alongside a team of researchers and clinicians.

What will the study tell us?

It is anticipated that the findings from this study will provide information and a greater understanding of the impact of trauma on children and families who have experienced a traumatic injury as well as the impact on staff. The findings may influence future clinical practice and enhance clinical outcomes for individuals who have experienced a potentially traumatic event. In addition results may influence quality of life in staff, clinical case loads and work place practices within PMH.

Do you have to take part?

Participation in the study is voluntary and you may withdraw at any time or refuse to answer any of the questions. Refusing participation or withdrawing from the study will not affect your employment at PMH.

What will you be asked to do if you decide to take part in this study?

If you agree to participate in this research you will complete a series of questionnaires with the researcher. The questionnaires will take no longer than one hour and will most likely take place at PMH. You will not be made to answer any questions that make you feel uncomfortable. Six months after you have completed the first series of questionnaires you will be asked to complete the questionnaires again.

What do you have to do to be in the study?

Work on the burns ward, ward 5A or be in the Neuro-rehab team, and be willing to participate.

Is there likely to be any benefit to participating in the study?

Early identification of psychological distress may lead to improved quality of life in the future.

Is there likely to be any benefit to other people in the future?

It is anticipated that the findings from this study will provide information and a greater understanding of the experience of staff within PMH who are exposed to paediatric trauma. This data is important to describe the phenomena and provide direction for future studies. The findings may also lead to an improvement or change in work place practices, which will ultimately improve the quality of life of staff at PMH.

What are the possible risks and/ or side effects?

There are no significant risks to participation. If you do become upset during the questionnaire or require follow up support, this will be provided through the Department of Health counselling Service.

What are the possible discomforts and/ or inconveniences?

The time required to complete the questionnaires (one hour) may be an inconvenience for you.

Where is your information kept?

Data collected will be de-identified and stored on the researcher's password-protected computer which will be stored in a locked cupboard when not in use. Collected data will be retained for five years after the completion of the study in a locked filing cabinet in the Department of Paediatric Rehabilitation.

What about my privacy?

All data will be de-identified by a member of the research team who does not work at PMH. This will ensure your anonymity and confidentiality is upheld at all times. Line managers, supervisors, heads of departments or colleagues at PMH will never be shown the data collected.

Who has approved the study?

PMH Human Ethics Committee and the Human Research Ethics Committee from ECU have approved this research.

Who to contact for more information about this study?

If you would like any more information about this study, please do not hesitate to contact a member of the research team listed below, they are very happy to answer your questions.

Who to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: (08) 9340 8222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

THANK YOU FOR YOUR TIME

Sarah McGarry

Occupational Therapist

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Appendix G: Consent Form



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service

Paediatric Trauma: The Impact on Children, Parents and Staff

FORM OF CONSENT (For Adult)

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I .....

have read

Given Names

Surname

the information explaining the study entitled:

Paediatric Trauma: The Impact on Children, Parents and Staff

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I understand I may withdraw from the study at any stage and withdrawal will not interfere with routine care.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

Dated ..... day of ..... 20 .....

Signature .....

I, ... have explained the above to
(Investigator's full name)

the signatory who stated that he/she understood the same.

Signature .....

CHILD ASSENT FORM

Paediatric Trauma: The Impact on Children, Parents and Staff

Verbal assent will be obtained from the child at the following time points during the study. If the child agrees to continue a tick must be placed in the box. If the child does not want to continue a cross must be placed in the box.

Time point	Time point	Child agrees?
1.	Details of the study explained and child asked if they would like to continue	
1.	Child would agrees to participate in the interview	

Appendix H: Parent Assessment Battery

Demographic Questionnaire (Department of Health and Ageing, 2004)

1. What is your age?

Less than 25 years
25-34
35-44
45-54
55-64
65-74
75-84
85+

2. Which of the following describes you?

Male ☐

Female ☐

3. In which country were you born?

Australia	
England	
Scotland	
New Zealand	
Italy	
Greece	
Croatia	
Lebanon	
Saudi Arabia	
China	
Vietnam	
Other: please specify	

4. Do you speak a language other than English at home?

No, English only	
Yes, Italian	
Yes, Greek	
Yes, Cantonese	
Yes, Mandarin	
Yes, Arabic	
Yes, Lebanese	
Yes, Vietnamese	
Yes, Creole	
Yes, Gruinji	
Yes, Other: please specify	

5. Are you Aboriginal or Torres Strait Islander Origin?

No ☐

Yes, Aboriginal ☐

Yes, Torres Strait Islander ☐

For persons of both Aboriginal and Torres Strait Islander origin, mark both 'yes' boxes.

6. What is your marital status?

Married	
Living with a partner/de facto	
Widowed	
Divorced	
Separated	
Never married	
Don't know	
Other, please specify	

7. If you responded in question 6. (above) that you were widowed divorced or separated, how long have you been widowed, divorced or separated.

(Years) Answer 0 if less than 1 year

8. What is the highest level of primary or secondary school you have completed?

Still at school	
Did not go to school	
Year 8 or below	
Year 9 or equivalent	
Year 10 or equivalent	
Year 11 or equivalent	
Year 12 or equivalent	
Don't know	

9. Which of the following best describes the setting in which you live? *Please tick one box*

Private residence (e.g. owning or purchasing, public/private rental) ☐

Partially supported living (e.g independent living unit within a retirement village) ☐

Fully supported living (e.g. short term crisis facility, hostels for people with disabilities) ☐

Temporary shelter ☐

Other, please specify :

10. Who else lives in your household?

You can tick more than one box.

No one, I live alone ☐

Spouse/Partner ☐

Children ☐

Brothers/Sisters ☐

Other relatives ☐

Non family members ☐

Anyone else, please specify:

11. Are you currently in paid employment?

Yes ☐

Please specify: Full time ☐

Part time ☐

No ☐

No, I have retired
Don't know ☐

12. Which income bracket best describes your household?

\$78,000 or more per year
\$52,000 to less than \$78,000 per year ☐
\$41,600 to less than \$52,000 per year ☐
\$36,400 to less than \$41,600 per year ☐
\$31,200 to less than \$36,400 per year ☐
\$20,800 to less than \$26,000 per year ☐
\$15,600 to less than \$20,800 per year ☐
\$10,400 to less than \$15,600 per year ☐
\$8,300 to less than \$10,400 per year ☐
\$6,200 to less than \$8,300 per year ☐
\$4,200 to less than \$6,200 per year ☐
\$2,200 to less than \$4,200 per year ☐
Nil income ☐
Negative income ☐
Don't know ☐

13. Do you currently receive a pension, allowance or benefit?

Yes ☐
No ☐
Don't know ☐

14. If you answered Yes to question 13 (above), what kind of benefit do you receive?

Age pension ☐
Repatriation pension ☐
Veteran's pension ☐
War widow's pension ☐
Widow's pension (excluding war widows pension) ☐
Invalid or disability ☐
Allowance pension ☐
Sickness allowance ☐
Don't know ☐
Other ☐
Please specify ☐

15. Do you have a diagnosed mental illness?

No ☐
Yes ☐
If Yes, Please specify _____

Parent Questions	Yes	No
Did you see the incident (accident) in which your child got hurt?		
Were you with your child in an ambulance or helicopter on the way to the hospital?		
When your child was hurt (or when you first heard it had happened), did you feel really helpless, like you wanted to make it stop happening but you couldn't?		
Does your child have any behaviour problems or problems paying attention?		

This questionnaire asks you questions that relate to factors that occurred before, during or after the traumatic event. Circle the response that best describes how much you **agree** with the following statements.

Q		Not at all	To a small extent	To a moderate extent	To a large extent	Totally
1	I have needed professional help to deal with emotional problems in the past					
2	Previously traumatic events have impacted negatively on my life in the past (e.g., assault, sexual abuse, previous combat duty, natural disasters, witnessing a traumatic event).					
3	In the past I was able to talk about my thoughts and feelings with my family members or friends					
4	In the past I was satisfied with the support that I had from my friends and family					
5	At the time of the event I felt terrified, helpless or horrified					
6	At the time of the event, I thought I was about to die					

Q		Not at all	To a small extent	To a moderate extent	To a large extent	Totally
7	I have felt irritable or angry since the event					
8	I have found it difficult to concentrate on what I was doing or things going on around me since the event					
9	I am confident that I can deal with the financial stressors that may arise as a consequence of the event					
10	I can accept what happened to me					

For each item please mark an “x” in the box below that best indicates how much you agree with the following statements as they apply to you over the last **month**. If a particular situation has not occurred recently, answer to how you think you would have felt.

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
1.	I am able to adapt when changes occur					
2.	I have at least one close and secure relationship that helps me when I am stressed.					
3.	When there are no clear solutions to my problems, sometimes fate or god can help					
4.	I can deal with whatever comes my way					
5.	Past successes give me confidence in dealing with new challenges and difficulties					
6.	I try to see the humorous side of things when faced with problems					
7.	Having to cope with stress can make me stronger					
8.	I tend to bounce back after illness, injury or other hardships					

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
9.	Good or bad, I believe that most things happen for a reason					
10.	I give my best effort no matter what the outcome may be					
11.	I believe I can achieve my goals, even if there are obstacles					
12.	Even when things look hopeless, I don't give up					
13.	During times of stress/crisis, I know where to turn for help					
14.	Under pressure, I stay focused and think clearly					
15.	I prefer to take the lead in solving problems rather than letting others make all the decisions					
16.	I am not easily discouraged by failure					
17.	I think of myself as a strong person when dealing with life's challenges and difficulties					

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
18.	I can make unpopular or difficult decisions that affect other people, if it is necessary					
19.	I am able to handle unpleasant or painful feelings like sadness, fear and anger					
20.	In dealing with life's problems, sometimes you have to act on a hunch without knowing why					
21.	I have a strong sense of purpose in life					
22.	I feel in control of my life					
23.	I like challenges					
24.	I work to attain my goals no matter what roadblocks I encounter along the way					
25.	I take pride in my achievements					

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
26.	Even when things look hopeless, I don't give up					
27.	During times of stress/crisis, I know where to turn for help					
28.	Under pressure, I stay focused and think clearly					
29.	I prefer to take the lead in solving problems rather than letting others make all the decisions					
30.	I am not easily discouraged by failure					
31.	I think of myself as a strong person when dealing with life's challenges and difficulties					
32.	I can make unpopular or difficult decisions that affect other people, if it is necessary					

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
33.	I am able to handle unpleasant or painful feelings like sadness, fear and anger					
34.	In dealing with life's problems, sometimes you have to act on a hunch without knowing why					
35.	I have a strong sense of purpose in life					
36.	I feel in control of my life					
37.	I like challenges					
38.	I work to attain my goals no matter what roadblocks I encounter along the way					
39.	I take pride in my achievements					

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to your child's event. How much were distressed or bothered by these difficulties?

		Not at all	A little bit	Moderately	Quite a bit	Extremely
1.	Any reminder brought back feeling about it					
2.	I had trouble staying asleep					
3.	Other things kept making me think about it					
4.	I felt irritable and angry					
5.	I avoided letting myself get upset when I thought about it or was reminded of it					
6.	I thought about it when I didn't mean to					
7.	I felt as if it hadn't happened or wasn't real					
8.	I stayed away from reminders about it					
9.	Pictures about it popped into my head					
10.	I was jumpy and easily startled					

		Not at all	A little bit	Moderately	Quite a bit	Extremely
11.	I tried not t think about it					
12.	I was aware that I still had a lot of feelings about it, but I didn't deal with them					
13.	My feelings about it were kind of numb					
14.	I found myself acting or feeling like I was back at that time					
15.	I had trouble falling asleep					
16.	I had waves of strong feelings about it					
17.	I tried to remove it from my memory					
18.	I had trouble concentrating					

		Not at all	A little bit	Moderately	Quite a bit	Extremely
19.	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart					
20.	I had dreams about it					
21.	I felt watchful and on guard					
22.	I tried not to talk about it					

Please read each statement and circle a number 0, 1, 2, or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0. Did not apply to me
- 1. Applied to me to some degree, or some of the time
- 2. Applied to me to a considerable degree, or a good part of the time
- 3. Applied to me very much, or most of the time

1.	I found it hard to wind down	0	1	2	3
2.	I was aware of dryness of my mouth				
3.	I couldn't seem to experience any positive feeling at all				
4.	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)				
5.	I found it difficult to work up the initiative to do things				
6.	I tended to over-react to situations				
7.	I experienced trembling (e.g. in the hands)				
8.	I felt that I was using a lot of nervous energy				
9.	I was worried about situations in which I might panic and make a fool of myself				
10	I felt that I had nothing to look forward to				
11	I found myself getting agitated				
12	I found it difficult to relax				
13	I felt down-hearted and blue				
14	I was intolerant of anything that kept me from getting on with what I was doing				
15	I felt I was close to panic				

16	I was unable to become enthusiastic about anything				
17	I felt I wasn't worth much as a person				
18	I felt that I was rather touchy				
19	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)				
20	I felt scared without any good reason				
21	I felt that life was meaningless				

End of questionnaire - Thank you

Appendix J: Staff Assessment Battery

Demographic Questionnaire (Department of Health and Ageing, 2004)

1. What is your age?

Less than 25 years
25-34
35-44
45-54
55-64
65-74
75-84
85+

2. Which of the following describes you?

Male ☐ Female ☐

3. In which country were you born?

Australia	
England	
Scotland	
New Zealand	
Italy	
Greece	
Croatia	
Lebanon	
Saudi Arabia	
China	
Vietnam	
Other: please specify	

4. Do you speak a language other than English at home?

No, English only	
Yes, Italian	
Yes, Greek	
Yes, Cantonese	
Yes, Mandarin	
Yes, Arabic	
Yes, Lebanese	
Yes, Vietnamese	
Yes, Creole	
Yes, Gruinji	
Yes, Other: please specify	

5. Are you Aboriginal or Torres Strait Islander Origin?

No ☐

Yes, Aboriginal ☐

Yes, Torres Strait Islander ☐

For persons of both Aboriginal and Torres Strait Islander origin, mark both 'yes' boxes.

6. What is your marital status?

Married	
Living with a partner/de facto	
Widowed	
Divorced	
Separated	
Never married	
Don't know	
Other, please specify	

7. If you responded in question 6. (above) that you were widowed divorced or separated, how long have you been widowed, divorced or separated.

(Years) Answer 0 if less than 1 year

8. What is the highest level of primary or secondary school you have completed?

Still at school	
Did not go to school	
Year 8 or below	
Year 9 or equivalent	
Year 10 or equivalent	
Year 11 or equivalent	
Year 12 or equivalent	
Don't know	

9. Which of the following best describes the setting in which you live? *Please tick one box*

Private residence (e.g. owning or purchasing, public/private rental) ☐

Partially supported living (e.g independent living unit within a retirement village) ☐

Fully supported living (e.g. short term crisis facility, hostels for people with disabilities) ☐

Temporary shelter ☐

Other, please specify :

10. Who else lives in your household?

You can tick more than one box.

No one, I live alone ☐

Spouse/Partner ☐

Children ☐

Brothers/Sisters ☐

Other relatives ☐

Non family members ☐

Anyone else, please specify:

11. Are you currently in paid employment?

Yes ☐

Please specify: Full time ☐

Part time ☐

No ☐

☐

No, I have retired
Don't know ☐

12. Which income bracket best describes your household?

\$78,000 or more per year
\$52,000 to less than \$78,000 per year ☐
\$41,600 to less than \$52,000 per year ☐
\$36,400 to less than \$41,600 per year ☐
\$31,200 to less than \$36,400 per year ☐
\$20,800 to less than \$26,000 per year ☐
\$15,600 to less than \$20,800 per year ☐
\$10,400 to less than \$15,600 per year ☐
\$8,300 to less than \$10,400 per year ☐
\$6,200 to less than \$8,300 per year ☐
\$4,200 to less than \$6,200 per year ☐
\$2,200 to less than \$4,200 per year ☐
Nil income ☐
Negative income ☐
Don't know ☐

13. Do you currently receive a pension, allowance or benefit?

Yes ☐
No ☐
Don't know ☐

14. If you answered Yes to question 13 (above), what kind of benefit do you receive?

Age pension ☐
Repatriation pension ☐
Veteran's pension ☐
War widow's pension ☐
Widow's pension (excluding war widows pension) ☐
Invalid or disability ☐
Allowance pension ☐
Sickness allowance ☐
Don't know ☐
Other ☐
Please specify ☐

15. Do you have a diagnosed mental illness?

No ☐
Yes ☐
If Yes, Please specify _____

This questionnaire asks you questions that relate to factors that occur before, during or after stressful events. Circle the response that best describes how much you **agree** with the following statements.

Q		Not at all	To a small extent	To a moderate extent	To a large extent	Totally
1	I have needed professional help to deal with emotional problems in the past					
2	Previously traumatic events have impacted negatively on my life in the past (e.g., assault, sexual abuse, previous combat duty, natural disasters, witnessing a traumatic event).					
3	In the past I was able to talk about my thoughts and feelings with my family members or friends					
4	In the past I was satisfied with the support that I had from my friends and family					
5	At the time of the event I felt terrified, helpless or horrified					
6	At the time of the event, I thought I was about to die					

Q		Not at all	To a small extent	To a moderate extent	To a large extent	Totally
7	I have felt irritable or angry since the event					
8	I have found it difficult to concentrate on what I was doing or things going on around me since the event					
9	I am confident that I can deal with the financial stressors that may arise as a consequence of the event					
10	I can accept what happened to me					

For each item please mark an “x” in the box below that best indicates how much you agree with the following statements as they apply to you over the last **month**. If a particular situation has not occurred recently, answer to how you think you would have felt.

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
1	I am able to adapt when changes occur					
2	I have at least one close and secure relationship that helps me when I am stressed.					
3	When there are no clear solutions to my problems, sometimes fate or god can help					
4	I can deal with whatever comes my way					
5	Past successes give me confidence in dealing with new challenges and difficulties					
6	I try to see the humorous side of things when faced with problems					
7	Having to cope with stress can make me stronger					
8	I tend to bounce back after illness, injury or other hardships					

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
9	Good or bad, I believe that most things happen for a reason					
10	I give my best effort no matter what the outcome may be					
11	I believe I can achieve my goals, even if there are obstacles					
12	Even when things look hopeless, I don't give up					
13	During times of stress/crisis, I know where to turn for help					
14	Under pressure, I stay focused and think clearly					
15	I prefer to take the lead in solving problems rather than letting others make all the decisions					
16	I am not easily discouraged by failure					
17	I think of myself as a strong person when dealing with life's challenges and difficulties					

		Not true at all (0)	Rarely true (1)	Sometimes true (2)	Often true (3)	True nearly all the time (4)
18	I can make unpopular or difficult decisions that affect other people, if it is necessary					
19	I am able to handle unpleasant or painful feelings like sadness, fear and anger					
20	In dealing with life's problems, sometimes you have to act on a hunch without knowing why					
21	I have a strong sense of purpose in life					
22	I feel in control of my life					
23	I like challenges					
24	I work to attain my goals no matter what roadblocks I encounter along the way					
25	I take pride in my achievements					

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to your exposure to children's trauma. How much were you distressed or bothered by these difficulties?

		Not at all	A little bit	Moderately	Quite a bit	Extremely
1.	Any reminder brought back feeling about it					
2.	I had trouble staying asleep					
3.	Other things kept making me think about it					
4.	I felt irritable and angry					
5.	I avoided letting myself get upset when I thought about it or was reminded of it					
6.	I thought about it when I didn't mean to					
7.	I felt as if it hadn't happened or wasn't real					
8.	I stayed away from reminders about it					
9.	Pictures about it popped into my head					
10.	I was jumpy and easily startled					
11.	I tried not to think about it					
12.	I was aware that I still had a lot of feelings about it, but I didn't deal with them					
13.	My feelings about it were kind of numb					

		Not at all	A little bit	Moderately	Quite a bit	Extremely
14.	I found myself acting or feeling like I was back at that time					
15.	I had trouble falling asleep					
16.	I had waves of strong feelings about it					
17.	I tried to remove it from my memory					
18.	I had trouble concentrating					
19.	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart					
20.	I had dreams about it					
21.	I felt watchful and on guard					
22.	I tried not to talk about it					

Please read each statement and circle a number 0, 1, 2, or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0. Did not apply to me
- 1. Applied to me to some degree, or some of the time
- 2. Applied to me to a considerable degree, or a good part of the time
- 3. Applied to me very much, or most of the time

1.	I found it hard to wind down				
2.	I was aware of dryness of my mouth				
3.	I couldn't seem to experience any positive feeling at all				
4.	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)				
5.	I found it difficult to work up the initiative to do things				
6.	I tended to over-react to situations				
7.	I experienced trembling (e.g. in the hands)				
8.	I felt that I was using a lot of nervous energy				
9.	I was worried about situations in which I might panic and make a fool of myself				
10	I felt that I had nothing to look forward to				
11	I found myself getting agitated				
12	I found it difficult to relax				
13	I felt down-hearted and blue				
14	I was intolerant of anything that kept me from getting on with what I was doing				
15	I felt I was close to panic				
16	I was unable to become enthusiastic about anything				

17	I felt I wasn't worth much as a person				
18	I felt that I was rather touchy				
19	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)				
20	I felt scared without any good reason				
21	I felt that life was meaningless				

When you help people you have direct contact with their lives. As you may have found, your compassion for those you help can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a helper (health professional). Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the **last 30 days**.

		Never	Rarely	Sometimes	Often	Very often
1.	I am happy	1	2	3	4	5
2.	I am preoccupied with more than one person I help					
3.	I get satisfaction from being able to help people	1	2	3	4	5
4.	I feel connected to others	1	2	3	4	5
5.	I jump or am startled by unexpected sounds	1	2	3	4	5
6.	I feel invigorated after working with those I help	1	2	3	4	5
7.	I find it difficult to separate my personal life from my work as a helper	1	2	3	4	5
8.	I am not as productive at work because I am losing sleep over traumatic experiences of a person	1	2	3	4	5

		Never	Rarely	Sometimes	Often	Very often
9.	I think I might have been affected by the traumatic stress of those I help	1	2	3	4	5
10.	I feel trapped by my job as a helper	1	2	3	4	5
11.	Because of my helping, I have felt 'on edge' about various things	1	2	3	4	5
12.	I like my work as a helper	1	2	3	4	5
13.	I feel depressed because of the traumatic experiences of the people I help	1	2	3	4	5
14.	I feel as though I am experiencing the trauma of someone I have helped	1	2	3	4	5
15.	I have beliefs that sustain me	1	2	3	4	5
16.	I am pleased with how I am able to keep up with helping techniques and protocols	1	2	3	4	5

		Never	Rarely	Sometimes	Often	Very often
17.	I am the person I always wanted to be	1	2	3	4	5
18.	My work makes me feel satisfied	1	2	3	4	5
19.	I feel worn out because of my work as a helper	1	2	3	4	5
20.	I feel overwhelmed because my caseload/work seems endless	1	2	3	4	5
21.	I believe I can make a difference through my work	1	2	3	4	5
22.	I avoid certain activities or situations because they remind me of frightening experiences of the people I help	1	2	3	4	5
23.	I am proud of what I can do to help	1	2	3	4	5
24.	As a result of my helping, I have intrusive, frightening ,thoughts	1	2	3	4	5

		Never	Rarely	Sometimes	Often	Very often
25.	I feel 'bogged down' by the system	1	2	3	4	5
26.	I have thoughts that I am a 'success' as a helper	1	2	3	4	5
27.	I can't recall important parts of my work with trauma victims	1	2	3	4	5
28.	I am a very caring person	1	2	3	4	5
29.	I am happy that I chose to do this work	1	2	3	4	5

ID	
0	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9

Coping Scale for Adults

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Name / ID:

601

1	2	3	4	5
Doesn't apply or don't do it	Used very little	Used sometimes	Used often	Used a great deal

* When you are stressed at work (PMH), what do you do? *

REMEMBER: YOU ARE THINKING ABOUT A SPECIFIC CONCERN

1. Talk to others to see what they would do if they had the problem	1 2 3 4 5	25. Work hard	1 2 3 4 5
2. Shut myself off from the problem so that I can avoid it	1 2 3 4 5	26. Find a way to relax; for example, listen to music, read a book, play a musical instrument, watch television	1 2 3 4 5
3. Keep up with work as required	1 2 3 4 5	27. Release pressure by taking alcohol or cigarettes	1 2 3 4 5
4. Play sport	1 2 3 4 5	*28. I get sick; for example, headache, stomach ache	1 2 3 4 5
5. Let the Lord take care of my worries	1 2 3 4 5	29. Wish a miracle would happen	1 2 3 4 5
6. Seek help from a qualified person	1 2 3 4 5	30. Don't share my problems with other people	1 2 3 4 5
7. Worry about my future	1 2 3 4 5	31. Work on my self image	1 2 3 4 5
8. Protect my self esteem	1 2 3 4 5	32. Assess the situation	1 2 3 4 5
*9. I get stressed out and despair	1 2 3 4 5	33. Create a humorous diversion	1 2 3 4 5
10. Keep my long term goals clear	1 2 3 4 5	34. Go for a work-out at the gym	1 2 3 4 5
11. Spend time with close friends	1 2 3 4 5	35. Look on the bright side of things and think of all that is good	1 2 3 4 5
12. Cry or scream	1 2 3 4 5	36. Develop a plan of action	1 2 3 4 5
13. Positive self-talk	1 2 3 4 5	37. Worry about what is happening	1 2 3 4 5
14. Make time for friends or family	1 2 3 4 5	38. Improve my appearance	1 2 3 4 5
15. Keep my feelings to myself	1 2 3 4 5	39. Organise an action or petition regarding my concern	1 2 3 4 5
16. Focus on what's most important	1 2 3 4 5	40. Get into or improve on existing special relationships; for example, husband, wife, boy/girl friend	1 2 3 4 5
17. Talk to others and give each other support	1 2 3 4 5	41. Hope that the problem will sort itself out	1 2 3 4 5
18. Work at solving the problem to the best of my ability	1 2 3 4 5	42. Criticise myself	1 2 3 4 5
19. Put effort into my work	1 2 3 4 5	43. Keep others from knowing what's worrying me	1 2 3 4 5
20. Keep fit and healthy	1 2 3 4 5	44. Think about what I am doing and why	1 2 3 4 5
21. Remember those who are worse off so my troubles don't seem so bad	1 2 3 4 5	45. Try to be funny	1 2 3 4 5
22. Pray for help and guidance so that everything will be all right	1 2 3 4 5	46. Find a way to let off steam; for example, cry, scream, drink, take drugs	1 2 3 4 5
23. Get professional help or counselling	1 2 3 4 5		
24. Worry about my happiness	1 2 3 4 5		

CONTINUE ON NEXT PAGE ...

ID				
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0
1	2	3	4	5
6	7	8	9	0

Coping Scale for Adults

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Name / ID:

601

1	2	3	4	5
Doesn't apply or don't do it	Used very little	Used sometimes	Used often	Used a great deal

* When you are stressed at work (PMH). What do you do? *

REMEMBER: YOU ARE THINKING ABOUT A SPECIFIC CONCERN

47. Try to have a cheerful outlook on life	1 2 3 4 5	66. Spend more time with my husband/ wife/boy/girl friend	1 2 3 4 5
48. Pray for the Lord to look after me	1 2 3 4 5	67. Join with people who have the same concern	1 2 3 4 5
49. Organise a group to deal with the concern	1 2 3 4 5	68. Take my frustrations out on others	1 2 3 4 5
50. Improve my relationship with others	1 2 3 4 5	69. Imagine that things will work out well	1 2 3 4 5
51. Get annoyed at myself	1 2 3 4 5	70. See myself as being at fault	1 2 3 4 5
52. Go to meetings which look at the problem	1 2 3 4 5	71. Get support from others such as parents or friends	1 2 3 4 5
53. Try to make close friends with a guy or girl, husband or wife	1 2 3 4 5	72. Discuss the problem with qualified people	1 2 3 4 5
54. Daydream about how things will turn out well	1 2 3 4 5	73. Make time for leisure activities	1 2 3 4 5
55. Think of different ways of dealing with the problem	1 2 3 4 5	74. List any other things you do to cope with your concern/s	
56. Blame myself	1 2 3 4 5		
57. Don't let others know how I am feeling	1 2 3 4 5		
58. Consciously 'block out' the problem	1 2 3 4 5		
59. Talk to other people about my concern to help me sort it out	1 2 3 4 5		
60. Tell jokes	1 2 3 4 5		
61. Ask a professional person for help	1 2 3 4 5		
62. Be happy with the way things are	1 2 3 4 5		
*63. I suffer headaches or stomach aches	1 2 3 4 5		
64. Worry about what will happen to me	1 2 3 4 5		
65. Put the problem out of my mind	1 2 3 4 5		