What is Trauma Informed Care in Paediatric Oncology?

Volume One

Child cancer FOUNDATION

About the Author

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The Child Cancer Foundation and Author of this report would like to acknowledge and thank Massey Universities Professor Kirsty Ross for peer reviewing this report.

ISBN Number 978-1-0670625-1-4

Tō tuāoma timatatanga
Ō kawenga pikau mahi
Ka hāere tonu ia ra, ia ra
Mō ō ratou oranga

Your journey began
With challenges day after day
With integrity and commitment
We support you and your
whānau with empathy

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Introduction

Through our commitment to continuous quality improvement, the Foundation strives to be at the forefront of evidence informed practice. That is, in part, why we commissioned this important piece of research into Trauma Informed Care (TIC). Much of what we do is work to help children and families manage through the trauma of a diagnosis, treatment and sadly for some families, the loss of a child. For many, the trauma of childhood cancer diagnosis doesn't stop at the conclusion of treatment but continues for many years into adolescence and adulthood.

What is also striking is that for around 30% of siblings of a brother or sister diagnosed with childhood cancer, the post traumatic trauma they experience is the same or similar to the child with the cancer diagnosis. This is supported by other research the Foundation has investigated.

We must also acknowledge the impacts of colonisation on Māori who are more likely to experience situational, cumulative and intergenerational trauma. This is discussed in a separate but equally important companion report. We have produced this as a separate, stand-alone report due to the complexity and importance we place on constructively designing and delivering our services for Māori whānau and have engaged with mana whenua to do so.

Importantly, the report also addresses the impact of working in paediatric oncology and the trauma this may have not only on the Foundation team but also the wider workforce. The report illustrates the mahi that organisations can undertake to help their staff manage the trauma they may experience due to working in this space.

What is most heartening from these reports is that the service model the Foundation uses is very much grounded in a trauma informed care model. This is not to say there is not more work we need to do. Specifically, how we work with siblings, Māori and Pacific Peoples are all areas for increased investment. The research also suggests the need for a system-wide approach to Trauma Informed Care, so how we can encourage other parts of the system to support a trauma informed model of care is an area for us to investigate further.

I hope you find these reports into Trauma Informed Care as insightful and thought provoking as we here at Child Cancer Foundation have.

Ngā mihi nui

Monica Briggs
Chief Executive

Dan Te Whenua-Walker
Chair, CCF

Reremoana Hammond
Deputy Chair, CCF

Executive Summary

The research found that the nearly universal nature of trauma means that by the time Child Cancer Foundation staff are meeting a newly diagnosed tamariki and their whānau for the first time, the whānau is most likely to have already been traumatised. Further, medical diagnosis and treatments are likely to traumatise or re-traumatise whānau if care is not taken to lessen its impacts.

Child Cancer Foundation has been using "Family Centred" care methods for many years, and these methods overlap with emerging trauma informed approaches to care. Arguably, Child Cancer Foundation's trauma informed care cultural journey has already started.

Research shows significant differences in traumatic experiences between the patient, their siblings, parents and other whānau members. It also shows that in clinical settings, trauma informed care methods can increase individual resilience and healing by avoiding re-traumatisation and empowering the tamariki and their whānau.

Published peer reviewed research at this time focuses on trauma informed care in clinical settings. Few papers discuss or even refer to non-clinical paediatric oncology support services. The best emerging advice and resources (which are limited) are available from other organisations working in the non-clinical space. The various models explored is the subject of Volume Three of this report.

In Aotearoa New Zealand, toitū te Tiriti[1] requires partnering with tangata whenua to take a wider approach to trauma informed care to specifically address the prevalence of historic and intergenerational traumas as a result of colonisation and racism. Further, the literature on trauma informed care is largely a Western, Educated, Industrialised, Rich and Democratic (WEIRD)[2] clinical construct that focuses on the individual, heavily informed by the American Substance Abuse and Mental Health Services Administration department (SAMHSA)[3] model, with the majority of reviewed papers identifying United States based work as foundational. This foundation has an individualistic cultural basis and may not be suitable for an Aotearoa New Zealand context. There is a deeper discussion of this in Volume Two of this report.

Post traumatic stress symptoms are frequently found in siblings, parents and other whānau members of the tamariki with cancer. While most whānau show high degrees of resilience, many likely experience one or more Post Traumatic Stress Symptoms as a result of the cancer journey experience. Paediatric Medical Traumatic Stress is the term given to these post traumatic stress symptoms and is used as a clinical model in the United States to understand and guide health interventions.

Trauma informed approaches also accrue health benefits to staff working with whānau. Trauma informed approaches support staff to minimise their own vicarious trauma, which in turn has improved health service outcomes for whānau and reduces staff churn and related costs for Child Cancer Foundation. It also plays a compliance role with regard to the NZ Health and Safety at Work Act 2015, which requires that employers have a duty of care to ensure the psychological health of their employees. This requires organisations to understand and take reasonable steps to address psychological harm in the workplace.

The likely benefits to tamariki with cancer, whānau and Child Cancer Foundation staff of continuing to develop our trauma informed approach appears compelling for whānau, volunteers and staff.

By openly and publicly engaging with the community and discussing the challenges, pitfalls and methods of its trauma informed journey, Child Cancer Foundation "walks the talk" of its values and provides valuable advice and references for the Aotearoa New Zealand health and charities sectors. This will contribute to the development of a stronger, healthier and more equitable community for all New Zealanders.

[1] *Honouring the Treaty of Waitangi.*

[2] *WEIRD is a term coined by Joseph Henrich to describe a bias in published psychological research. Ref: Muthukrishna M, et.al 'Beyond Western, Educated, Industrial, Rich, and Democratic (WEIRD) Psychology: Measuring and Mapping Scales of Cultural and Psychological Distance', Psychological Science, p. 678.*

[3] *The SAMHSA has been an influential developer of the concept of trauma informed care.*

Key Terms and Glossary

Acute Stress Disorder	A diagnosis made in the acute phase that is confirmed if the patient meets criteria for 9 of 14 symptoms.
Acute trauma	Short term response to a traumatic event that usually results in the 'flight/fight' response.
Adverse Childhood Experiences (ACE)	A trauma occurring in childhood including emotional, sexual and physical abuse, neglect, and family dysfunction. Research shows these traumas increase the likelihood of adult disease.
Burnout	Burnout is the cumulative psychological strain and state of exhaustion from working under challenging conditions.
Chronic trauma	Trauma resulting from exposure to stressors that are repetitive or prolonged.
Compassion fatigue	Compassion fatigue is the emotional exhaustion from helping others and can lead to reduced capacity to be empathetic.
Complex trauma	Trauma resulting from multiple overlapping or successive events that may or may not be related.
Dissociation	A mental process where a person disconnects from their thoughts, feelings, memories, behaviour or sense of identity. Usually arises as a reaction to traumatic or painful events.
Hauora	Health, wellbeing.
Historic trauma	Traumatic events that are experienced so broadly that they affect an entire culture (e.g. colonisation, slavery) and is likely experienced over multiple generations.
Kaupapa Māori	Māori ideology, a philosophical doctrine incorporating the knowledge, skills, attitudes and values of Māori communities.
Leukaemia	Leukaemia is the name given to a group of cancers that develop in the bone marrow. Leukaemia develops in blood cells that have undergone a malignant change.
Paediatric Medical Traumatic Stress (PMTS)	A set of psychological and physiological responses of tamariki and their whānau to pain, injury, serious illness, medical procedures and invasive or frightening treatment experiences.
Post Traumatic Stress Disorder (PTSD)	A mental health condition triggered by a traumatic event, either experiencing it or witnessing it in person. Symptoms may include flashbacks, nightmares, and severe anxiety, as well as uncontrollable thoughts about the event.
Post Traumatic Stress Symptoms (PTSS)	Post Traumatic Symptoms that may be present without meeting the full criteria for a diagnosis of PTSD.

Resilience	The protective mechanisms that have the potential to enhance individual recovery after a traumatic event.
Secondary traumatic stress	The emotional stress response experienced by a person who is exposed to the trauma, pain and/or suffering of others. It is an occupational hazard for persons working with traumatised people. Secondary traumatic stress is also known as compassion fatigue and vicarious trauma.
Tamariki	Child or Children.
Tikanga	Correct procedure, custom, habit, lore, method, manner.
Tino Rangatiratanga	Tino Rangatiratanga relates to sovereignty, autonomy, control, self-determination and independence. The notion of Tino Rangatiratanga asserts and reinforces the goal of Kaupapa Māori initiatives, allowing Māori to control their own culture, aspirations and destiny.
Trauma	Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being.[4]
Trauma Informed Approach	A programme, organisation or system that is trauma informed realises the widespread impact of trauma and understands potential paths for recovery; recognises the signs and symptoms of trauma in clients, whānau, staff and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatisation.
Trauma Informed Care (TIC)	Trauma informed care means a programme of care that seeks to avoid re-traumatisation by using a trauma informed approach.
Vicarious resilience	The inspiration drawn from observing others who are experiencing difficult or traumatic circumstances.
Vicarious trauma	Vicarious trauma is the cumulative effect from prolonged exposure to the trauma of others. It involves harmful changes in an individual's personal beliefs, worldview, attitude, and sense of safety.
Whānau	Extended family or family group.

[4] *Substance Abuse and Mental Health Services Administration (SAMHSA) Trauma and Justice Strategic Initiative 2012, p.2*

Background to the Research

While paediatric cancer can be considered a physical condition, the experience of having cancer and being treated for cancer is psychologically challenging. Individuals, both the diagnosed tamariki and their whānau, are likely to experience trauma symptoms. Additionally, this experience may compound other traumas individuals may have already experienced. For example, living through a disaster like an earthquake, or being impacted by family violence.

Consequently, many healthcare settings (medical practices, hospitals etc.) have amended clinical care practices to incorporate trauma informed methods with the intention of improving care outcomes, lessening the trauma of diagnosis and treatment and lessening the risk of re-triggering pre-existing trauma(s). Child Cancer Foundation wishes to better understand trauma informed approach (TIA) and trauma informed care (TIC) methods and explore how its own practices might be adapted to incorporate these methods.

Child Cancer Foundation is a charity established with the purpose "To walk alongside and support all children and their families on their cancer journey and work on advancing improvements to child cancer care."[5] As a result of this focus, psychosocial support services provided by the Whānau Support Department have focused for many years on the whole whānau, not just the tamariki in care. This "Family Centered" approach is very similar to trauma informed approaches to care services.

The unique and overlapping aspects of Family Centered and trauma informed care is described in the graphic below.[6] Noting the overlap between the Family Centered approach and a Trauma Informed approach, Child Cancer Foundation has arguably already started its trauma informed workplace change journey.

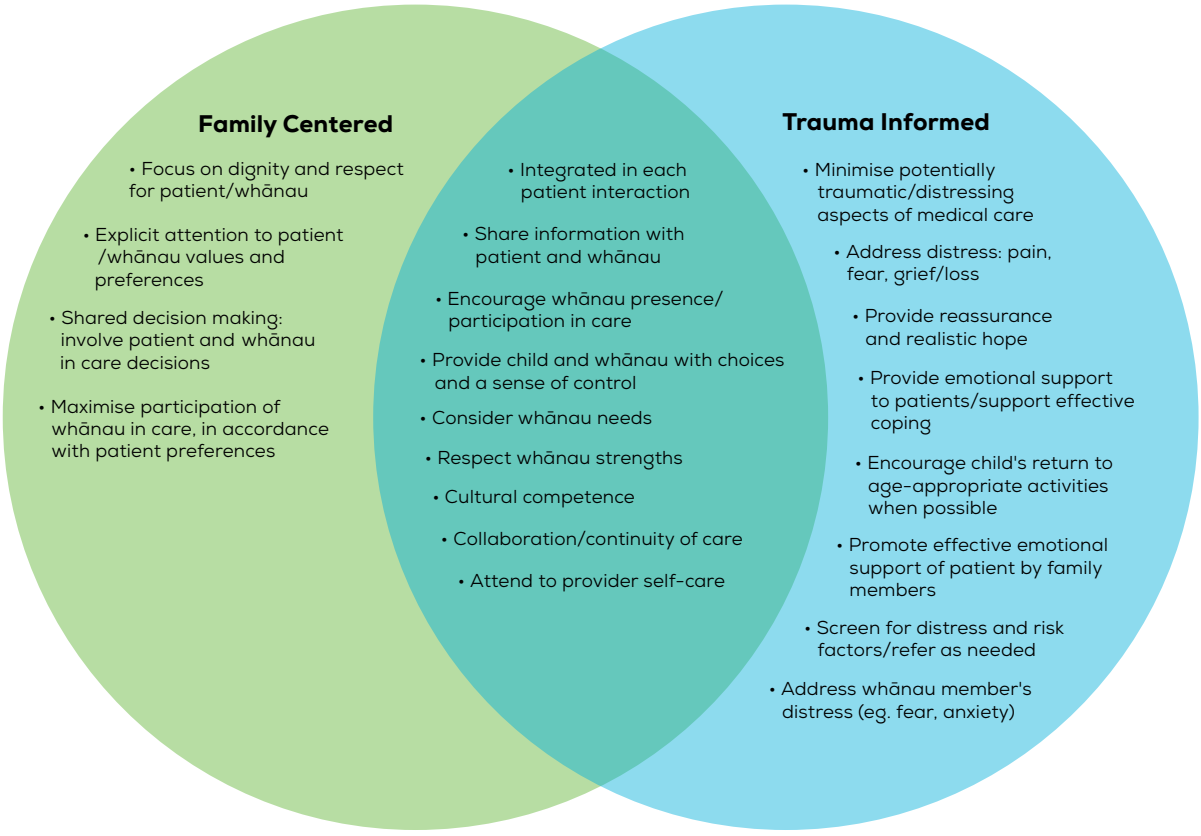


Figure 1: Marsac M., Unique and Overlapping Elements of Family Centred and Trauma Informed Paediatric Care

[5] *NZ Child Cancer Foundation Strategic Plan 2022 – 2025, p.3.*

[6] *Marsac M., Implementing a Trauma Informed Approach in Pediatric Health Care Networks, 2016, p. 73.*

Review Objectives

The objectives of this project are:

1. Deliver a literature review of trauma informed care in paediatric oncology using New Zealand, Australia, the United States and United Kingdom based information sources.
2. Explore high-level options to enhance core CCF Whānau Support by introducing trauma informed care methods into CCF models of care.
3. Present key findings to the CCF LG Research Day on 27th November.

Research Methodology

This review was informed by the literature scoping review framework,[7] namely:

1. Identify the research question.
2. Identify relevant information sources (databases, key journals and relevant organisations).
3. Develop search terms.
4. Paper selection. Determine what criteria will be used to determine inclusion.
5. Chart the data. Review common themes across studies and align with research question.
6. Collate, summarise and report results.

The full Research Plan, including detailed method and exclusion criteria is attached at Appendix One.

Results

In summary, it is clear from the published peer-reviewed research that little research has been published on the application of trauma informed care in paediatric oncology support services. The proliferation and still increasing numbers of published papers on trauma informed care and trauma informed approach have to date been focused primarily on clinical interactions in clinical settings like medical centres and hospitals. As the phenomenon of trauma informed approach gains in popularity thanks to the improved health and wellbeing outcomes this approach can generate, it is anticipated that the current clinical focus is likely to widen to include other partner organisations like psychosocial charities operating in this space.

Reports published by non-clinical organisations working in the trauma field provide additional material on the application of a trauma informed approach. A number of those models have been included in Volume Three of this report.

Literature research outcomes

Overall, 41 papers were identified in the database and journal search, after removing duplicates. These papers were abstract, using the inclusion criteria to identify papers for a full-text review. This left a total of 9 journal papers for full review.

Key themes taken from the detailed review of these papers, published articles and practice materials from organisations working in this area are included in Appendix One. A more fulsome presentation and discussion of the main themes and models is the subject of this report.

Geographic jurisdictions

Based on the lead author, the majority of papers were published in the United States. Interestingly, trauma informed care in the United Kingdom context appears more closely associated with trauma with physical injury and as experienced in a Hospital Emergency Department with trauma informed care as a method appearing to not be as mature in the United Kingdom as in the United States.

There is less published research on trauma informed care from Aotearoa New Zealand and Australia. However, the Māori approach to trauma informed care has been developing since 2017. Māori approaches to trauma informed care are described in more detail in Volume Two of this report.

[7] *Arksey H., & O'Malley L., Scoping studies: Towards a methodological framework, International Journal of Social Research Methodology, 2005, p. 19.*

Introduction to Trauma

What is trauma?

According to the Royal Australian & New Zealand College of Psychiatrists, "Trauma can present in various forms and in varied contexts and may be defined as the broad psychological and neurobiological effects of an event, or series of events, which produces experiences of overwhelming fear, stress, helplessness or horror. The Diagnostic and Statistical Manual of Mental Disorders delimits such events to those which "may cause death or threaten death, serious injury, or sexual violence".[8] Te Pou o te Whakaaro Nui[9] (Te Pou) defines trauma informed care as "the experience of violence and victimisation including sexual abuse, physical abuse, severe neglect, loss, domestic violence and/or the witnessing of violence, terrorism or disasters. … a person's response that involves intense fear, horror and helplessness. Extreme stress that overwhelms the person's capacity to cope." Te Pou emphasises that the context of the trauma is important and that the trauma should be central to support services, rather than "peripheral issue associated with behaviour".[10]

The Substance Abuse and Mental Health Services Administration[11] (SAMHSA) in the United States defines trauma as follows: "Individual trauma results from an event, series of events or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being." Examples of individual trauma include Adverse Childhood Experiences (ACEs), intimate partner violence, being a displaced person or refugee or being subject to political terror or war.

Worldwide research indicates that over 70% of people experience at least one traumatic event in their lifetimes with almost 31% being exposed to four or more such events.[12] In Aotearoa New Zealand, a survey carried out in 2019 found that 55% of respondents reported experiencing one adverse childhood experience, while 12% experienced four adverse childhood experiences before the age of 18 years.

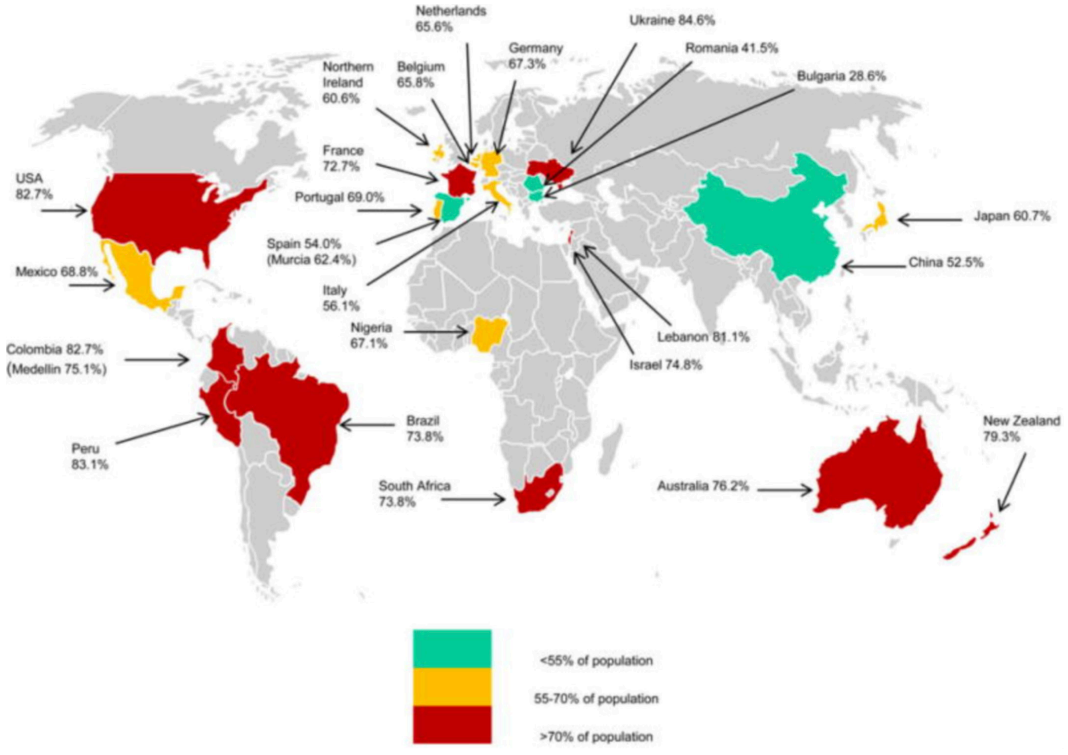


Figure 2: Benjet C., et.al. Prevalence of exposure to any traumatic event in each survey of the 24 countries

[8] *Trauma informed practice: position statement, Clinical Guidelines Publications Library, Royal Australian and New Zealand College of Psychiatrists, PS #100, 2020.*

[9] *Te Pou o te Whakaaro Nui is the New Zealand national mental health agency.*

[10] *Pihama L., et.al., Investigating Māori approaches to trauma informed care, Journal of Indigenous Wellbeing, Te Rau Matatini, 2017, p. 21.*

[11] *SAMHSA has been a key developer of the concept of trauma informed care. In 2005 SAMHSA launched the Nation Centre for Trauma Informed Care to provide technical assistance, education and resources to support the adoption of trauma informed care principles. In 2014 SAMHSA published a guide that identifies six principles for implementing trauma informed care which are outlined further in Volume Three of this report.*

[12] *Benjet, C., et.al., The epidemiology of traumatic event exposure worldwide: Results from the world mental health survey consortium. Psychological Medicine, 2016, 46(2), p. 328.*

However, trauma may also be experienced by a group, a community or a society. A group trauma can be experienced as a result of oppression on the basis of race, religious, gender or sexuality. A mass trauma may also be experienced at a society level as a result of an event affecting a region, like an earthquake or a tsunami.

Trauma may present as "complex trauma" which is trauma "resulting from exposure to severe stressors that

1. are repetitive or prolonged,
2. involve harm or abandonment by caregivers or other ostensibly responsible adults, and
3. occur at developmentally vulnerable times in the victim's [sic] life, such as early childhood: … but can also occur later in life."[13]

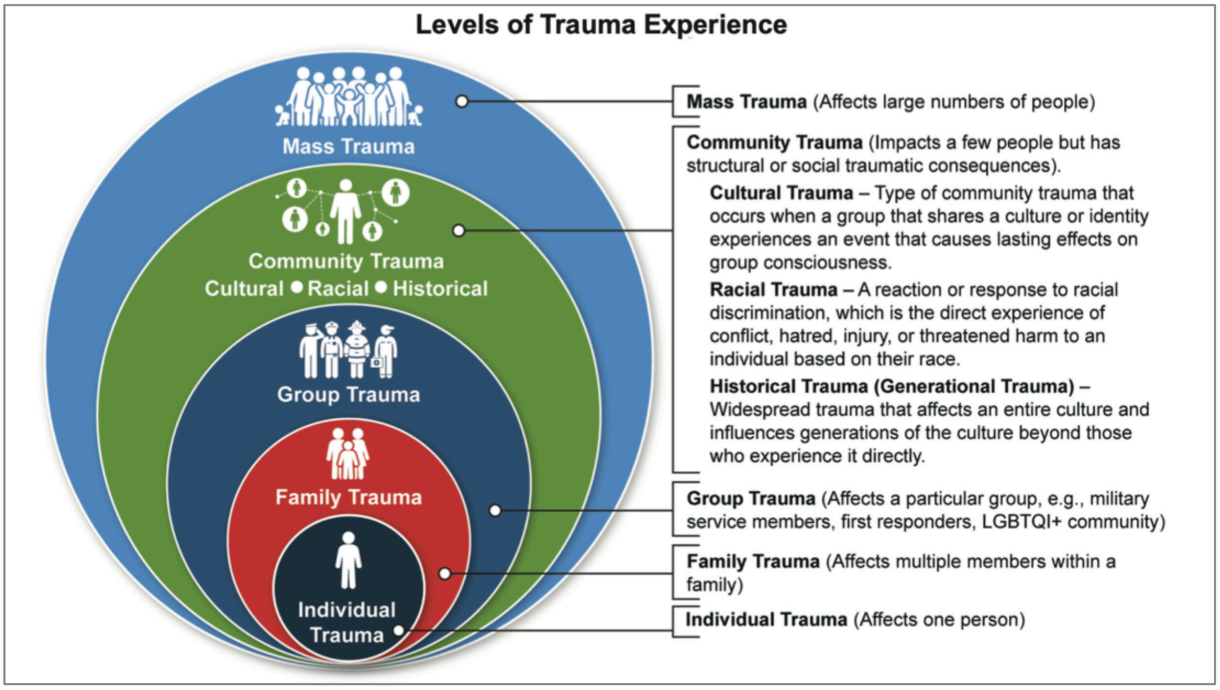


Figure 3: SAMHSA, Practical Guide for Implementing a Trauma informed Approach, 2023

Historic trauma or intergenerational trauma refers to events that are so broadly experienced that they affect an entire culture. Examples include; slavery and torture of African Americans, the holocaust in World War II and the Khmer Rouge in Cambodia. Historic and intergenerational traumas have more recently been identified by multiple indigenous scholars as a limitation on current 'Western' or WEIRD[14] definitions of trauma. A key criticism is that the dominant perspective of what trauma is and therefore its treatment "Fail to account for long-term chronic and complex individual and collective trauma. In additional they do not allow for experiences of historical trauma due to assimilative colonial practices which have occurred for indigenous populations worldwide."[15] In Aotearoa New Zealand, Māori scholars have argued that there is a "need for therapies firmly rooted within cultural contexts"[16] because racism continues to impact 93% of Māori every day.[17]

Long and sustained trauma(s), sometimes referred to as Type II trauma[18], can alter the growth of a person's brain over time. From a neurobiological perspective trauma is an experience or experiences which "activate the stress response systems in such an extreme or prolonged fashion as to cause alternations in the regulation and functioning of these systems."[19] Children are particularly vulnerable

[14] *WEIRD means Western, Educated, Industrialised, Rich and Democratic.*

[15] *Wirihana & Smith (2014) quoted in Pihama L., et.al., "He Oranga Ngākau: Māori Approaches to Trauma Informed Care", Te Kotahi Research Institute, 2020, p.20.*

[16] *Ibid., p. 19.*

[17] *Donaldson W., "Trauma informed approach: An update of the literature, Te Pou, 2024, p.7.*

[18] *Courtois, op.cit., p.8.*

[19] *Perry, D. P., Child Maltreatment: A neurodevelopmental perspective on the role of trauma and neglect in psychopathology in Beauchaine, T., & Hinshaw S. P., (editors), Child and Adolescent Psychopathology, Wiley & Sons, New Jersey, 2008, p 94.*

to sustained trauma as a result of the "rapid and important neural changes taking place".[20] Any damage to normal brain growth in childhood may result in dysregulation in other parts of the brain. The younger a child is during the traumatic experience the higher the likelihood that they will experience health problems in adulthood.[21]

It is important to note that not all traumatic stress responses to medical events are pathological. Some reactions are the entirely rational and normal response to an abnormally upsetting situation.[22]

Trauma is a nearly universal human experience.

The Adverse Childhood Experience (ACE) Study in the United States (1995-1997), was conducted by the Centres for Disease Control and the Kaiser Permanente Health Care Organisation. Focused on three categories of adverse childhood experiences (abuse, neglect and household dysfunction[23]) the data from this study demonstrated that 63.9% of the child population have experienced at least one adverse childhood experience and 12.5% had experienced four or more.[24] For this reason, adverse childhood experiences are considered pervasive in general populations, regardless of social-economic, gender or cultural grounds.

In New Zealand, a population study conducted from 2017-2019 showed that adverse childhood experiences were prevalent and reoccurring with 55% of respondents experiencing one adverse childhood experience before the age of 18 years and 11.6% reporting three or more adverse childhood experiences.[25] In the Māori population, 78% reported at least one adverse childhood experience with 27.4% experiencing four or more adverse childhood experiences. Multiple studies have demonstrated that multiple adverse childhood experiences are predictive of premature mortality and adult chronic health conditions like heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease.[26] Based on this data, the likelihood is that most whānau Child Cancer Foundation are serving have already experienced trauma by the time staff first meet them.

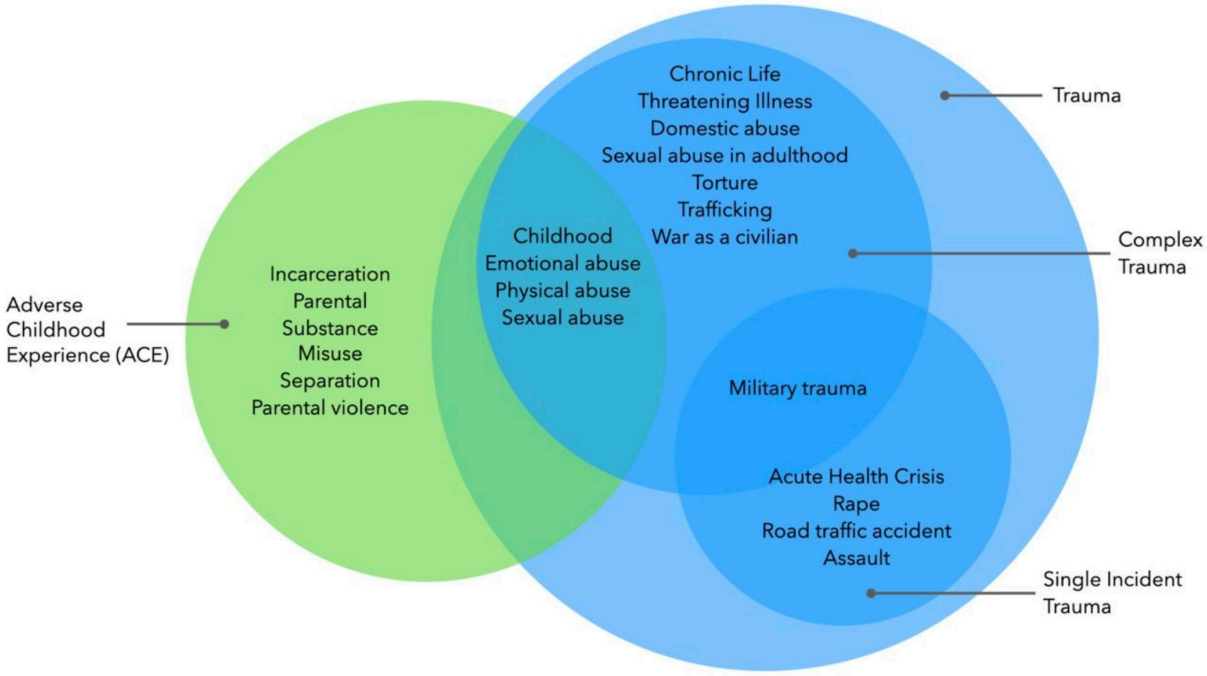


Figure 4: Relationship between ACE's and trauma (NHS Education for Scotland 2017.)

[20] *Ibid., p 95.*

[21] *Ibid., p. 99.*

[22] *Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M.A., & Rourke, M., An Integrative Model of Pediatric Medical Traumatic Stress, Journal of Pediatric Psychology, 2006, 31(4), p.348.*

[23] *IThe ACE categories include experiences like: psychological, physical, or sexual abuse; violence against mother; living with household members who were substance abusers, mentally ill or suicidal, or imprisoned.*

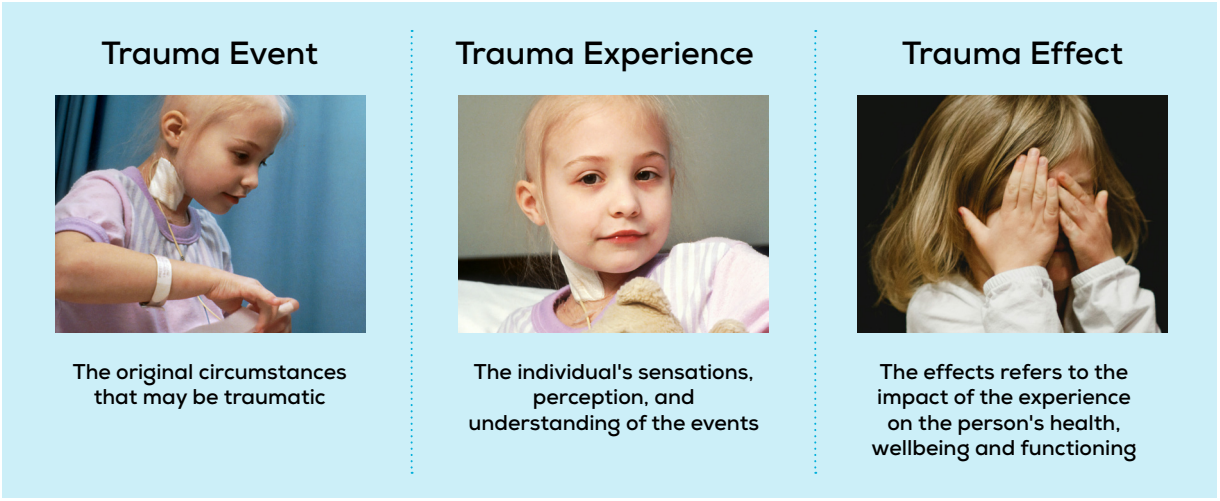
[24] *Felitti V.J., et.al., Relationship of childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study, American Journal of Preventative Medicine, 1998, p. 245.*

[25] *Fanslow J., et.al. Adverse childhood experiences in New Zealand and subsequent victimization in adulthood: Findings from a population-based study. Child Abuse & Neglect, 2021, p. 11- 12.*

[26] *Dong, M., et.al. 2004: Bellis, M.A., et.al., 2015: Kelly-Irving, M., et.al., 2013 & Giovanelli, A., et.al., 2016.*

A Trauma has three components.

Trauma has three components, known as the "Three E's" of Trauma.[27] The trauma **event** is the circumstance that creates the trauma effect. The trauma **effect** is an objective assessment of wellbeing. However, the trauma **experience** is a subjective experience and a significant predictor of individual trauma. Two or more people may experience the same trauma event but because their subjective experience of the event may differ, it may result in a variable trauma experience.[28]



Previous life experiences, social support, personal coping skills and community reactions can all affect how a person experiences trauma.[29] In particular, the extent to which the individual assesses their level of life-threat is key. Where individuals consider their life threat is high, this increases the risk of future Post Traumatic Stress Disorder (PTSD).

Acute, Chronic and Complex Trauma.

As demonstrated by the Adverse Childhood Experiences study[30], trauma is not always singular. Acute trauma is characterised by a short-term response to a singular traumatic event that typically results in the "flight/fight" response[31], e.g. Car accident or assault. Chronic trauma means a series of traumatic incidences that may be repeated or prolonged. If a response in the acute phase does not resolve, that trauma can progress to a chronic (longer-term) trauma response. Complex trauma means multiple over-lapping or successive events that may or may not be related. In the DSM–5, chronic trauma has the following symptom clusters (1) hyperarousal, (2) avoidance behaviours, (3) intrusive memories, (4) altered cognition and moods.

What is trauma in childhood cancer?

Research carried out in the United States by Anne E Kazak at the Children's Hospital of Philadelphia and summarised in the table on the next page[30], showed that aspects of paediatric oncology treatments can be traumatising (or re-traumatising). It also shows that children and mothers consider different things to be more or less traumatic. The colours on the table reflect differences in trauma experience between the child and their mother. This serves as a reminder that tamariki and their whānau may see and experience the cancer journey very differently.

[27] *SAMHSA, Practical Guide for Implementing a Trauma informed Approach, U.S. Department of Health and Human Services, 2023, p. 2.*

[28] *Pai, A.L.H, & Kazak, A.E., Pediatric medical traumatic stress in pediatric oncology: family systems interventions, Current Opinion in Pediatrics, 2006, p. 558.*

[29] *SAMHSA, Practical Guide for Implementing a Trauma informed Approach, 2023, p. 3.*

[30] *Felitti, op.cit., p.245.*

[31] *Feriante J., et.al., Acute and Chronic Mental Health Trauma, US National Library of Medicine, 2023, https://www.ncbi.nlm.nih.gov/books/NBK594231/, Retrieved 26 November 2024.*

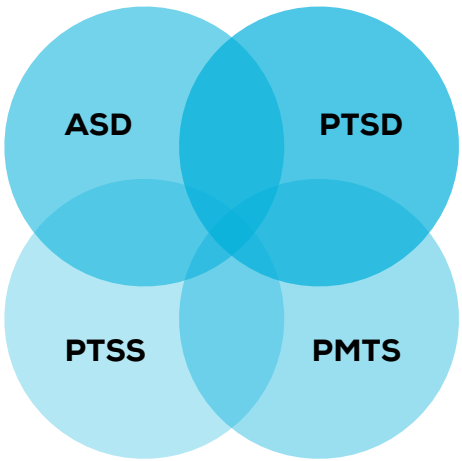
What is most traumatic?[32]	
Child cancer survivors	Mothers of cancer survivors
1. Injections	1. Worried about relapse
2. Losing hair	2. Pain
3. Staying in the hospital	3. Scared about death
4. Pain	4. Diagnosis – finding out
5. Bone marrow procedures	5. Know others that died
6. Know others that died	6. Feeling sad/scared
7. Scared about death	7. Staying in hospital
8. Worried about relapse	8. Injections
9. Feeling sad/scared	9. Bone marrow procedures
10. Diagnosis – finding out	10. Losing hair

Further work carried out by Kazak showed that in a group of 119 mothers and 52 fathers, all except one parent reported post traumatic stress symptoms. In the families with two participating parents, nearly 80% had at least one parent with moderate-to-severe Post Traumatic Stress Symptoms (PTSS).[33]

Trauma symptoms and conditions.

Trauma symptoms and conditions may be symptomatic of more than one diagnosis. Additionally, research into many conditions is ongoing, so WEIRD medical understanding of these conditions and their treatments are still emerging.[34] The graphic below outlines four areas of trauma that are:

Acute Stress Disorder
Mental disorder with diagnosis involving nine or more symptoms from the diagnostic categories that last between 3 days and one month following exposure to the traumatic event and are not attributable to any other condition



Post Traumatic Stress Disorder
Mental disorder that involves disturbing or distressing symptoms after exposure to a traumatic experience

Post Traumatic Stress Symptoms
The symptoms associated with PTSD

Paediatric Medical Traumatic Stress
The symptoms associated with PTSD, which are related only to medical trauma in a paediatric population

[32] *HealthCareToolBox, Medical Care is scary but it can be traumatizing (website) https://www.healthcaretoolbox.org/medical-care-is-scary-but-can-it-be-traumatizing Retrieved 27 Nov 2024.*

[33] *Kazak A. E., et. Al. Posttraumatic stress symptoms during treatment in parents of children with cancer, Journal of Clinical Oncology, 2005, p.7405.*

[34] *Davidson, C. A., Kennedy, K., Jackson, K. T., Trauma informed Approaches in the Context of Cancer Care in Canada and the United States: A Scoping Review. Trauma Violence Abuse, 2023, p. 2983.*

Acute Stress Disorder (ASD) is a diagnosis made in the acute phase, typically between 3 days to one month following a traumatic event. There are 14 separate ASD symptoms and a diagnosis is confirmed if a patient meets the criteria for nine. If symptoms persist beyond the acute period (a month from the traumatic event) a clinician would reassess the patient for Post Traumatic Stress Disorder. For this reason, Acute Stress Disorder is considered a predictor of the potential development of Post Traumatic Stress Disorder. (Incidental research from the US identified that out of 140 families recently diagnosed with childhood cancer, 50% of mothers and 40% of fathers met the full criteria for Acute Stress Disorder).

Post Traumatic Stress Disorder (PTSD) is a psychiatric disorder that may occur from experiencing or witnessing a traumatic event(s) or set of circumstances. This may be "emotionally or physically harmful or life-threatening and may affect mental, physical, social and/or spiritual well-being."[35] Symptoms of Post Traumatic Stress Disorder fall into four categories: involuntary memories (intrusion); avoiding reminders of the traumatic event, including being reluctant to talk about the event (avoidance); distorted thoughts about the event, self, causes or consequences of the event (alterations in cognition and mood) and hypersensitivity, recklessness or being easily startled, problems with concentrating or sleeping (alterations in arousal and reactivity). For a person to be diagnosed with Post Traumatic Stress Disorder, symptoms must last for more than a month and cause significant distress.[36] The disorder was first identified in childhood cancer survivors in 1985 and 1989[37] which led to field trials for the diagnosis to be included in the DSM-4.[38] Subsequent research showed "low rates of Post Traumatic Stress Disorder in the cancer-survivor population but substantial rates of subclinical Post Traumatic Stress Symptoms, particularly for parents and for young adults who had cancer during childhood."[39]

Post Traumatic Stress Symptoms (PTSS) are symptoms of Post Traumatic Stress Disorder that may present after experiencing or witnessing a traumatic event. A symptom or multiple symptoms may present, without meeting the full diagnostic criteria for Post Traumatic Stress Disorder.

Paediatric Medical Traumatic Stress (PMTS) is a "set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences."[40] Paediatric Medical Traumatic Stress is considered a traumatic stress model and a predictable cluster of symptoms for understanding psychological reactions to medical treatment and while related to Post Traumatic Stress Disorder and Acute Stress Disorder is not itself a diagnosis.[41] The model is discussed in full in Volume Three of this report.

The impact of trauma.

"Trauma is similar to a rock hitting the water's surface. The impact first creates the largest wave, which is followed by ever-expanding, but less intense, ripples. Likewise, the influence of a given trauma can be broad, but generally, its effects are less intense for individuals further removed from the trauma; eventually, its impact dissipates all around. For trauma survivors, the impact of trauma can be far-reaching and can affect life areas and relationships long after the trauma occurred.

This analogy can also broadly describe the recovery process for individuals who have experienced trauma and for those who have the privilege of hearing their stories. As survivors reveal their trauma-related experiences and struggles to a counsellor or another caregiver, the trauma becomes a shared experience, although it is not likely to be as intense for the caregiver as it was for the individual who experienced the trauma. The caregiver may hold onto the trauma's known and unknown effects or may consciously decide to engage in behaviours that provide support to further dissipate the impact of this trauma and the risk of secondary trauma."

~ Excerpt from SAMSHA Treatment Improvement Protocol 57[42]

[35] *Taylor-Desir, M., American Psychiatric Association, https://www.psychiatry.org/patients-families/ptsd/what-is-ptsd 2022, Retrieved: 9 December 2024.*

[36] *Ibid., Taylor-Desir, M. https://www.psychiatry.org/patients-families/ptsd/what-is-ptsd 2022.*

[37] *Nir (1985) and Pot-Mees (1989) quoted in Kazak, A., et.al., Journal of Pediatric Psychology, 2004, p. 211.*

[38] *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), American Psychiatric Association, 1994.*

[39] *Kazak, op.cit., 2004., p. 212.*

[40] *National Child Traumatic Stress Network, Pediatric Medical Traumatic Stress: A Comprehensive Guide for Health Care Providers, 2003, p.2.*

[41] *Kazak, op.cit., 2004, p. 343.*

[42] *Substance Abuse and Mental Health Services Administration (SAMHSA), Trauma informed Care in Behavioural Health Services, Treatment Improvement Protocol Series 57. HHS Publication No. (SMA) 3-4801, Rockville, MD: Substance Abuse and mental Health Services Administration, 2014, p. 30.*

Resilience

Resilience can be defined as the speedy recovery of good mental health during and after a period of adversity or trauma.[43] Research into resilience is relatively recent and seeks to understand the 'protective mechanisms' that have the potential to shield individuals from developing anxiety and/or trauma symptoms as a result of their experience. Protective factors can include things like having an optimistic worldview or growing up in a supportive family. What exactly resilience is varies between authors and studies and, in more recent times, resilience is being thought of as a 'process of dynamic adaption', where protective factors and a dynamic process are thought to create a resilient outcome.[44]

One study identified that for tamariki, one of the single most powerful protective mechanisms for childhood adversity is the presence of a trusted 'always available adult'. This was associated with lower levels of unhealthy adulthood behaviours and health conditions.[45] Other studies have identified the complex interplay of physical, emotional and environmental factors along with the type and intensity of the stressor (the traumatising event). Further, this occurs within highly variable family, community and societal contexts.[46]

A further study involving 308 parents of children undergoing cancer treatment found that 3 types of psychological interventions (resilience training, self-disclosure and peer support) significantly enhanced parents' overall resilience.[47] Multiple studies of adult patients have illustrated the effectiveness of clinical interventions to enhance protective mechanisms including: developing emotional regulation skills[48] and reducing symptoms of depression.[49]

Additionally, in a traumatic circumstance, while an individual might present as shocked or traumatised, or suffering from a mental symptom or multiple trauma symptoms, it does not mean that they are non-resilient.[50] Understanding the protective factors available to each individual and how they might be optimally used will help children and their whānau to respond resiliently.

Trauma related conditions, risk and protective factors[51]

Risk factors	Conditions related to trauma	Protective factors
Lack of safe, stable, nurturing relationships Young age Female gender for intimate partner violence/sexual violence Male gender for community violence Minority status (race, ethnicity, religion, sexual orientation, gender identity, other) Psychiatric illness Substance use Disability (physical and mental) Family history of violence Homelessness Poverty	Psychiatric illnesses, (anxiety, depression, PTSD, cPTSD, suicidality) Chronic illnesses (heart, lung, liver and other diseases) Sexually transmitted infections including HIV Sleep disorders Unwanted pregnancy and pregnancy at early age Childhood learning and behaviour problems Poor educational attainment Substance use Homelessness Premature death (due to poor health, homicide, suicide) Future victimisation or perpetration of violence	Supportive family relationships Well-resourced, safe communities Financial security Employment Stable housing Higher educational status Higher brain executive function Community engagement Good health

According to the US Centre for Disease Control and Prevention, the single most important child resilience factor is "The presence of a safe, stable nurturing adult caregiver who is consistently present in that child's life."[52] The value of this consistent safe adult, which has been substantiated through multiple studies[53], is that person has the effect of providing the child with a level of personal safety which mitigates trauma and increases future positive health outcomes for the child.

[43] *Schellekens, M. P., et.al., Resilience in the face of cancer: On the Importance of defining and Studying Resilience as a Dynamic Process of Adaption, Current Oncolocgy, 31, 2024, p. 4003.*

[44] *Ibid, p.4005.*

[45] *Kimberg, L., et.al., in Gerber M. R., (ed.), Trauma Informed Healthcare Approaches, Springer Nature, 2019, p. 30.*

[46] *Schellekens, op.cit., p. 4006.*

[47] *Luo, Yh., Xia, W., He, Xl. et al. Psychological interventions for enhancing resilience in parents of children with cancer: a systematic review and meta-analysis. Support Care Cancer, 2021, p. 7109.*

[48] *Lin, C.; Diao, Y.; Dong, Z.; Song, J.; Bao, C. The Effect of Attention and Interpretation Therapy on Psychological Resilience, Cancer-Related Fatigue, and Negative Emotions of Patients after Colon Cancer Surgery. Ann. Palliat. Med. 2020, p. 3261.*

[49] *Pan, S.; Ali, K.; Kahathuduwa, C.; Baronia, R.; Ibrahim, Y., Meta-Analysis of Positive Psychology Interventions on the Treatment of Depression, Cureus, 2022, Retrieved 4 December 2024. https://www.cureus.com/articles/83067-meta-analysis-of-positive-psychology-interventions-on-the-treatment-of-depression#!/.*

[50] *Schellekens, op.cit., p. 4007.*

[51] *Kimberg L., Trauma and Trauma informed care in King T.E., & Wheeler M.B. (eds), Medical management of vulnerable and under serviced patients: principles practice and populations, 2016, p. 31.*

[52] *Centre for Disease Control and Prevention, Essentials for Childhood Framework, p. 6.*

[53] *Robinson, L.R., Leeb, R.T., Merrick, M.T. et al., Conceptualizing and Measuring Safe, Stable, Nurturing Relationships and Environments in Educational Settings, Journal of Child and Family Studies, 2016, p. 1488.*

Trauma Informed Approach and Trauma Informed Care

A Trauma Informed Approach is a service delivery method. When trauma informed approaches are successfully used in healthcare and healthcare support services, those strategies will result in a Trauma Informed Care outcome. Trauma informed care is:

> *"grounded in an understanding of, and responsiveness to the impact of trauma, that emphasises physical, psychological and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment"*[54]

Trauma informed care came about largely as a growing recognition of rates of trauma in the lives of individuals accessing healthcare services.[55] Importantly, it is not about treating the source of the person's trauma(s), instead, it is a recognition that taking "universal trauma precautions" would enhance healthcare outcomes by understanding more thoroughly what was contributing to a person's distress.[56] A trauma precaution in this context is a strategy informed by "the effects of trauma on individuals and interactions into practice, consumer collaborations and systemic reviews of practice."[57]

The Substance Abuse and Mental Health Services Administration in the United States is the federal agency responsible for supporting mental health and substance abuse treatment and prevention services in the community. In 2014, Substance Abuse and Mental Health Services Administration published 'TIP 57: Trauma Informed Care in Behavioural Health Services'. This document is a foundational reference to trauma informed care practices and research in multiple jurisdictions around the world, including Aotearoa New Zealand.

Substance Abuse and Mental Health Services Administration advises that trauma informed care "involves vigilance in anticipating and avoiding institutional processes and individual practices that are likely to retraumatise individuals who already have histories of trauma, and it upholds the importance of consumer participation in the development, delivery, and evaluation of services."[58]

Substance Abuse and Mental Health Services Administration also advises that "integrating trauma informed care into behavioural health services provides many benefits not only for clients, but also for their families and communities, for behavioural health service organisations, and for staff."[59]

In the research and consultation work they carried out in 2012, the organisation identified that trauma informed care incorporates 3 core elements:

1. Realising the prevalence of trauma,
2. Recognising how trauma affects all individuals involved with the program, organisation, or system, including its own workforce, and
3. Responds by putting this knowledge into practice.

The US National Child Traumatic Stress Network (NCTSN) defines a trauma informed approach as "A service system in which all parties recognize and respond to the impact of traumatic stress on those who have contact with the system including children, caregivers, and service providers. Programs and agencies within such a system infuse and sustain trauma awareness, knowledge and skills into their organizational cultures practices, and policies. Programs, agencies and services providers:

1. Routinely screen for trauma exposure and related symptoms,
2. Use culturally appropriate, evidence-based assessment and treatment for traumatic stress and associated mental health symptoms;
3. Make resources available to children, families, and providers on trauma exposure, its impact, and treatment,

[54] *SHopper E. K., Bassuk E. L., & Olivet J., 2010, p.82*
[55] *Isobel S., The 'trauma' of trauma informed care, Australasian Psychiatry, 2021, p. 589.*
[56] *Isobel S., Trauma informed care: a radical shift or basic good practice? Australasian Psychiatry, 2016, p. 590.*
[57] *Ibid., p. 590.*
[58] *SAMHSA, op.cit., 2014, p. xix.*
[59] *SAMHSA, op.cit., 2014,p. 8.*

4. Engage in efforts to strengthen the resilience and protective factors of children and families impacted by and vulnerable to trauma,
5. Address parent and caregiver trauma and its impact on the family system,
6. Emphasize continuity of care and collaboration across child-service systems, and
7. Maintain an environment of care for staff that addresses, minimises, and treats secondary traumatic stress and that increases staff resilience."[60]

The NCTSN web-based network portal contains many resources for organisations wishing to learn more about an American styled trauma informed approach.[61]

Trauma informed ecosystem.

In clinical and allied support services the care that is provided is often delivered in collaboration with other organisations who also support some or all of the whānau's cancer journey. Organisations may include pharmacy and chemists, specialist accommodation (eg. Ronald McDonald House), nutritionists, blood transfusion services, transport, hospital wards, palliative care, counsellors and psychologists, schools and day care centres, churches, legal services and the local marae.

TIC Ecosystem

In order to avoid re-traumatising tamariki and their whānau, it is helpful to take an ecosystem approach and apply trauma informed care methods from diagnosis, to cancer treatment, care, discharge and follow up processes. To achieve the best trauma informed care outcome, all organisations in the ecosystem would understand the approaches being taken by each other and work collaboratively to minimise any possible re-traumatisation in the tamariki's ecosystem.

Compassion and cultural humility.

The skills and practices of compassion and cultural humility are critical to trauma informed care. Compassion is "a cognitive, affective, and behavioural process consisting of the following five elements that refer to both self- and other-compassion:

1. Recognizing suffering,
2. Understanding the universality of suffering in human experience,
3. Feeling empathy for the person suffering and connecting with the distress (emotional resonance),
4. Tolerating uncomfortable feelings aroused in response to the suffering person (e.g. distress, anger, fear) so remaining open to and accepting of the person suffering, and,
5. Motivation to act/acting to alleviate suffering." [62]

[60] *NCTSN, Creating trauma informed systems (webinar) https://www.nctsn.org/resources/creating-trauma informed-systems, Accessed 20 November 2024.*

[61] *https://www.nctsn.org/resources*

[62] *Strauss C., Lever Taylor B., Gu J., Kuyken W., Baer R., Jones F., & Cavanagh K., What is compassion and how can we measure it? A review of definitions and measures, Clinical Psychology Review, 2016, p. 19.*

Compassion is a foundational concept of many religions, but is closely associated with Buddhist philosophy. It is seen by Buddhists as being both an ethical and wise response to free others from suffering.[63] His Holiness the Dalai Lama advises that: "Genuine compassion has both wisdom and loving kindness. That is to say, one must understand the nature of the suffering from which we wish to free others (this is wisdom), and one must experience deep intimacy and empathy with other sentient beings (this is loving kindness)."[64]

Cultural humility is a practice or orientation where each individual recognises "their own inherent biases and adopts a mindset of lifelong learning towards working with diverse communities and a recognition of the role of power in health care interactions."[65] Cultural humility requires admitting that a single person "does not know, and is willing to learn from patients about their experiences, while being aware of one's own embeddedness in culture(s)."[66] It can be conceived as having several components: Openness; Self-awareness and self-critique; Egolessness; Supportive interactions and lifelong learning.[67] This approach recognises the complexity of cultures and the likelihood that individuals may "belong" to more than one cultural group. Perceptions of what cultural competency is can lead to circumstances where individuals stereotype or make inaccurate cultural assumptions. Cultures are not homogenous, although to an individual "outside" of that culture, they may appear so. An important difference between cultural competency and cultural humility is recognising "the role of power in healthcare interactions."[68] Some cultural groups have suffered "health related experimentation"[69] from healthcare service providers. As a result, interactions with healthcare service providers can increase feelings of vulnerability and powerlessness. The move from cultural competence to cultural humility signals healthcare services provider acceptance of the patient as the ultimate authority on their culture and how it impacts their lives.

Burnout, Vicarious Trauma and Compassion Fatigue.

Research demonstrates that working with tamariki and whānau in traumatic circumstances can involve considerable risk to healthcare providers. This has long been appreciated in the field of medicine however in more recent times studies are consistently showing that other allied fields e.g. counsellors, social workers, emergency first responders, law enforcement, journalists and insurance claim staff, have all been shown to varying degrees to be affected.[70]

The condition of burnout was identified in the 1970's amongst clinic workers in the United States. At the time it was thought to have three dimensions: "emotional exhaustion, depersonalisation and feelings of incompetence or reduced personal accomplishment."[71] Today, burnout is considered to be the result of demanding and stressful situations that progressively erode individual resilience and raise personal stress levels beyond the capacity of the individual's ability to cope. Symptoms include depression, loss of compassion and reduced feelings of accomplishment.[72]

Repeated exposure to the traumatic experiences or suffering of others, combined with high levels of distress that are often seen when people recount their experiences, has an impact on healthcare clinicians and service providers that is referred to as compassion fatigue. It is associated with the carer's understanding of another person's suffering and their personal desire to help. Compassion fatigue has been described as "too tired to care" and is characterised by a reduced interest in and capacity for the suffering of others.[73] Compassion fatigue is often also known as secondary traumatic stress. It differs from Burnout in that it comes about as a result of the compassionate connection made between carer and patient. Unlike burnout, the onset of compassion fatigue may in some circumstances be sudden and acute.[74] An enquiry into New Zealand social workers identified that it is common for practitioners to have to manage their own secondary trauma without support from their organisation.[75]

Vicarious trauma was described in the 1990's as trauma experienced by a carer as a result of proximity to another person's trauma, that has the ability to "cause alterations in cognition, beliefs and schemas as a result of observing or experiencing the trauma of others."[76] The changes experienced in carers as a result of a vicarious trauma are understood to impact the carer-patient relationship. Empathetic

[63] *His Holiness the Dalai Lama, "The power of compassion: A Collection of lectures by His Holiness the Dalai Lama, Harper Collins, New Delhi, 1995. p.48.*
[64] *Ibid., p. 49.*
[65] *Agner J., Moving from cultural competence to cultural humility in occupational therapy: a paradigm shift. American Journal of Occupational Therapy, 2020, p. 7.*
[66] *Lekas M., Rethinking Cultural Competence: shifting to cultural humility, Health Services Insights, 2020, p. 1.*
[67] *Vinson J., Majidi A., & George M., Cultural humility in Trauma informed Care, in Gerber M. R., Trauma informed Healthcare Approaches, Springer, 2019, p. 60.*
[68] *Ibid., p. 10.*
[69] *Pihama, op. cit., et.al., p. 23.*
[70] *Phelps A, Caring for Carers in the aftermath of trauma, Journal of Aggression, Maltreatment and Trauma, 2009, p. 318.*
[71] *Ibid., p. 315.*
[72] *Dunkley J., et.al., Vicarious traumatization: current status and future directions, British Journal of Guidance and Counselling, 2006, p.108.*
[73] *Phelps, op. cit., p. 316.*
[74] *Ibid, p. 317.*
[75] *Donaldson W., Trauma Informed Approach: An update of the literature, Te Pou, 2024, p.9.*
[76] *Isobel, op. cit., 2016, p. 590.*

engagement and personal identification with the plight of the patient is a key factor in the development of vicarious trauma. The vicarious trauma experience occurs when the carer, through compassionate intentions, becomes close to the patient to the extent that the patient's "thoughts and feelings, originating from their experiences" transfers to the carer.[77]

In Aotearoa New Zealand, a 2009 study revealed that caring induced trauma is insidious in nature and often leads to mental health nurses leaving the profession, "especially in circumstances where they did not understand what was happening to them."[78] It follows that a high degree of staff churn in carer roles leads to greater recruitment and staff replacement resourcing requirements and can also impact the quality of support and care provided as individuals with existing carer relationships finish their employment mid-way through a child's cancer journey.

Clarity of role, supervision and isolation have been found to affect the levels of stress experienced by carers.[79] Supervision and connectedness to team were all seen as factors that support the health and happiness of staff who work with people who may be or become traumatised.

Vicarious resilience.

Happily, not all carers find their work traumatising. Several studies have suggested that vicarious resilience (also known as compassion satisfaction) may be a protective factor and a way for individuals to build their personal resilience.[80] Vicarious resilience is understood to be the inspiration sometimes drawn from what we see other people doing, and how we are lifted up and encouraged by examples of the human spirit we see around us.

A study conducted in Ireland following the Omagh bombing in August 1998 followed 13 healthcare workers who treated the victims of the blast and collected data about their experience working with traumatised people. The results showed that team camaraderie amongst the workers, along with the satisfaction of seeing their patients recover, were the positive aspects of their experience. However, when individuals left the team and returned to their substantive positions, their reported levels of vicarious resilience dropped and many of them experienced post traumatic symptoms.[81]

For a detailed look at various Trauma Informed Care Models, please see Volume Three.

Conclusion

Post traumatic stress symptoms are frequently found in siblings, parents and other whānau members of the tamariki with cancer. While most whānau show high degrees of resilience, many likely experience one or more post traumatic stress symptoms as a result of the childhood cancer journey experience. Paediatric Medical Traumatic Stress is the term given to these post traumatic stress symptoms and is used as a clinical model in the United States to understand and guide health interventions.

Trauma informed approaches also accrue health benefits to staff working with whānau. Trauma informed approaches support staff to minimise their own vicarious trauma, which in turn has improved health service outcomes for whānau and reduces staff churn and related costs for Child Cancer Foundation. It also plays a compliance role with regard to the NZ Health and Safety at Work Act 2015, which requires that employers have a duty of care to ensure the psychological health of their employees. This requires organisations to understand and take reasonable steps to address psychological harm in the workplace.

The likely benefits to tamariki with cancer, whānau and Child Cancer Foundation staff of continuing to develop our trauma informed approach appears compelling for whānau, volunteers and staff.

By openly and publicly engaging with the community and discussing the challenges, pitfalls and methods of its trauma informed journey, the organisation "walks the talk" of its values and provides valuable advice and references for the Aotearoa New Zealand health and charities sectors. This will contribute to the development of a stronger, healthier and more equitable community for all New Zealanders.

[77] *Prasko J., et.al., Managing Transference and Countertransference in Cognitive Behavioral Supervision: Theoretical Framework and Clinical Application. Psychology Research and Behavior Management, 2022, p. 2130.*

[78] *Davies L., Vicarious Traumatisation: The Impact of Nursing upon Nurses, Te Herenga Waka-Victoria University of Wellington, 2009, p.147.*

[79] *Phelps op.cit., p. 318.*

[80] *Ibid, p. 321*

[81] *Collins S., Too tired to care? The psychological effects of working with trauma Journal of Psychiatric and Mental Health Nursing, 2003, p. 24.*

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Appendix One

Research Plan.

1. Identify the research question.

"What is known from existing literature about trauma informed approaches to paediatric oncology support services in New Zealand, Australia, United Kingdom and United States."

Material providing an overview of trauma informed care to patients and whānau will be relevant. It was agreed in consultation with CCF staff to restrict research to the four jurisdictions in order to keep the overall number of studies manageable and to avoid duplicating other literature searches that may already have been completed.

2. Identify relevant information sources (databases, key journals and relevant organisations).

Relevant journals were identified through preliminary searches on published scoping reviews, using Google Scholar. Backwards citation method[82] on published scoping studies was used to identify the commonly used journals within the jurisdictions outlined above.

a) Databases

Relevant peer reviewed journals were sourced from Davidson et.al. (2023). They are: PsycINFO, CINAHL, Medline, Ovid Embase and Scopus and PubMed. However, it is proposed that detailed research on each database not be completed. Instead, relevant scoping studies, completed by medically trained researchers, have been reviewed in detail. It is clear from those papers (listed in the reference section) that scoping studies in trauma informed care and paediatric oncology research has been completed and is both recent and thorough, so it would not add any additional value to recreate that work for USA and the UK jurisdictions. Instead, time would be spent focusing on researching more recent work from New Zealand and Australian jurisdictions.

A total of 12 scoping studies were identified using the search terms in Google Scholar. Of the 12 scoping papers, 4 studies were excluded using the inclusion criteria, leaving 8 for a full review.

b) Key journals

In Western medical science the longer standing academic journals are based primarily in the US and the UK. New Zealand and Australia have relatively few international standard peer reviewed journals. Further, in order to progress an academic career, publication in the more established prestigious journals results in higher citations and rankings. Relevant journal sources (for New Zealand and Australia) were identified using backwards citation method. Those searches resulted in the following journals:

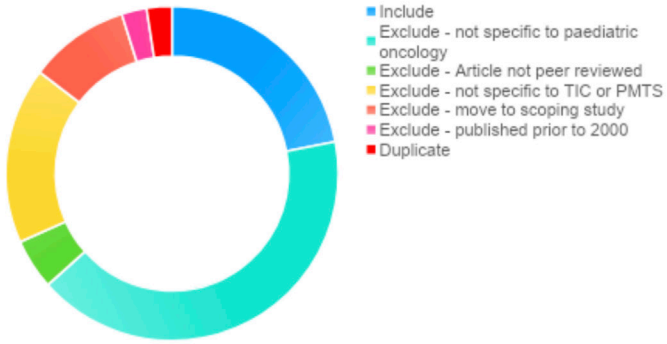
Academic Medicine
American Journal of Hospice and Palliative Medicine
American Psychologist
Australia and New Zealand Journal of Public Health
Child Maltreatment
Clinical Social Work Journal
CNS Spectrums
Families, Systems & Health
Health and Social Care in the Community
JAMA Paediatrics
Journal of Educational and Psychological Consultation
Journal of Evidence-Informed Social Work
Journal of Pediatric Psychology
Journal of Pediatric Hematology/Oncology
Journal of Pediatric Hematology/Oncology Nursing
Journal of Clinical Oncology
Journal of Indigenous Wellbeing
Journal of Trauma Stress
Journal of the American Academy of Child and Adolescent Psychiatry
Journal of the American Psychiatric Nurses Association
The Lancet, Psychiatry
Maternal and Child Health Journal
Medical Journal of Australia
Mental Health Review Journal
Paediatrics
Pediatric Blood and Cancer
Pediatric Cancer
Pediatric Hematology and Oncology
Pediatric Oncology
Psychiatric Nurses Association
Psycho Oncology
Psychosomatics
Social Work
Trauma, Violence and Abuse
The New Zealand Medical Journal

[82] *Backwards citation method is a research method that searches the reference sections of published journal papers to source relevant research material.*

Search terms were applied to each journal which resulted in identifying 41 possible papers.

An abstract review that applied the eligibility criteria to the content of the abstract of each paper was completed to determine papers for a full review. The graph below summarises the outcomes of the abstract review, which resulted in identifying 9 eligible papers for full review.

Journal Paper Abstract Review Summary



c) Relevant organisations

Relevant organisations were identified through a combination of google searches, backwards citation method and recommendations from CCF staff. Relevant organisations are listed below.

New Zealand

Child Cancer Network
ANZCHOG
Canteen NZ
Leukaemia and Blood Cancer NZ
Rei kotuku Charitable Trust
AYA Cancer Network Aotearoa
Starship Blood & Cancer Centre
Cancer Control Agency
Curekids
Cancer Society of New Zealand
Cancer Research Trust

United Kingdom

Cancer Research UK
Young Lives vs Cancer
Macmillan Cancer Support
Children's Cancer and Leukaemia Group
Children with Cancer UK
Solving Kids Cancer
Neuroblastoma UK
World Child Cancer
Together for Short Lives

Australia

Redkite
Children's Cancer Foundation
Canteen Australia
Children's Cancer Institute
Kids with Cancer Foundation
Zero Childhood Cancer
Phoenix Australia

United States of America

Alex's Lemonade Stand Foundation for Childhood Cancer
American Childhood Cancer Organisation
National Pediatric Cancer Foundation
Children's Cancer Research Fund
CureSearch for Children's Cancer
CancerCare
The National Children's Cancer Society
Riley Children's Health
ASK Childhood Cancer Foundation
The Childrens Cancer Foundation
Sunshine Kids Foundation
National Child Traumatic Stress Network
Health Care Toolbox

Each organisation's websites were searched using their embedded search engine. Where sites did not have an embedded search engine, site specific Google searches were completed using the search terms. If a site contained a 'Resources' or 'Publications' section or page, additional reviews of search terms in material titles were completed. Time was taken to consider 'handbooks' and other generically titled publications in order to ascertain any trauma informed care implementation activities.

3. Search terms and research limitations.

Note: English and American spelling variations. American spelling was used for US based journals and for American and Australian organisations. English spelling was used for Australian, New Zealand and United Kingdom organisations. The terms identified were informed by search terms used in the scoping studies.

Search terms	*Suffixes*
Trauma informed	Care
Paediatric cancer	Practice
Paediatric oncology	Childhood
Paediatric medical traumatic stress	Child

4. Paper selection.

CCF staff were consulted to determine paper inclusion criteria. The final criteria are:

i. Papers must report on the use of trauma informed care in a paediatric cancer care setting.

ii. Papers must report from relevant jurisdictions eg. New Zealand, Australia, United Kingdom and United States.

iii. Papers must be in English (Author is restricted to English).

iv. Exclude conference extracts.

v. Exclude blogs, 'how-to' advisory articles and opinion based articles.

vi. Exclude papers published prior to 2000.

Where abstract review allows, and if required to further reduce the papers for review, the additional secondary inclusion criteria are:

i. Papers report on trauma informed care in paediatric cancer care setting for children and whānau where the child is less than 20 years old,

ii. Papers report on peer-to-peer trauma informed care methods and opportunities, and,

iii. Papers report on trauma informed care methods in organisations that use voluntary workforce for some or all of their support services.

Not all information sources were able to be abstract screened. Alternative screening methodologies included reviewing 'Summary' or 'Introduction' sections of other published materials.

Note: These criteria present additional limitations on the research. Firstly, the selected jurisdictions are WEIRD[83] which does not take into account cultural differences[84] which research continues to show is relevant. For example, Māori, Pacific Peoples and East Asian nations. Further the Author has an Irish/Australian heritage and is not culturally competent to interpret material from other cultural groups.

When the inclusion criteria were applied to the 14 documents identified in the abstract review, a total of 9 journal articles were identified for a detailed review.

5. Chart the data. Review common themes across studies and align with research question.

Table 2 on the following page summarises the themes from the detailed review.

[83] *The majority of published peer reviewed scientific research comes from WIERD countries and a significant proportion of it comes from the United States. The jurisdictions in this research are predominantly WEIRD. WIERD is an acronym that standards for Western Industrialised Educated Rich and Democratic. That is, the data from this research relies on a largely monocultural western life experience and as a result may be limited in its application in other cultures. Cultural differences might include things like; an individualism or collective base to the dominant culture, aspects of masculinity, long-term orientation, or uncertainty avoidance.*

[84] *Cultural differences can include (but may not be limited to) individualism, indulgence, long-term orientation, masculinity, power distance and uncertain avoidance (degree to which a society tolerates ambiguity). (Muthukrishna M., et.al. 2020)*

Table 2: Research themes

Author Surname	Study key characteristics	Intervention contents	Intervention modes	Outcomes
Pai L.H. & Kazak A.E. (2006)	PMTS developed to guide psychosocial interventions, notably the PTSS of arousal, re-experiencing and avoidance. NCTSN materials for the 3 stages of PMTS are:			
	Stage 1: Pediatric Traumatic Stress Toolkit for Health Care Providers (incl. D-E-F protocol)..	DEF pocket card, PMTS case studies (for clinical staff). PMTS Information for parents.	One to one with patient and parents.	
	Stage 2: Surviving Cancer Competently Intervention Programme – Newly Diagnosed (SCCIP-ND): Family systems intervention, 3 x sessions.	Parent dyads[85] including: cognitive reappraisal. Group sessions: normalising thoughts, feelings and beliefs.	Tutoring to parents/caregivers in group. Digital family discussion groups.	2 month post-intervention, reduction in anxiety and PTSS.
	Stage 3: SCCIP-ND.	1 day, 4 session includes: x 2 cognitive behavioural tools, adversity – beliefs – consequences model and reframing.[86]	Group.	Significantly fewer arousal symptoms overall. Fathers reported fewer intrusive thoughts and arousal symptoms. Reduction in symptoms was less for mothers.
	Problem Solving Skills Training (PSST)	8 session intervention	Group *Also Spanish-speaking group	3 months post intervention mothers reported significant improvement in depression and anxiety. Single, young mothers tended to benefit most.
Marsac M.L., Kassam -Adams N., et.al (2016)	*This paper was an article review that indicated x 4 Trauma Informed Approaches. They are:			
	1. National Centre for Trauma Informed Care.	Book ref: TIP 57 - Trauma informed Care in Behavioural Health Services.	-	-

[85] *Parent dyads means mothers and fathers are taught in the same session.*

[86] *"Adversity referred to the common experience of having cancer or having a family member with cancer; beliefs were identified as thoughts about the adversities; and consequences were defined as emotions and behaviours in response to the adversity. Reframing involved the participants restructuring thoughts and beliefs about cancer to positively alter consequences. Examples of reframing used in SCCIP included teaching participants to accept the uncontrollable, focus on the controllable and use the positive." Pai L.H. & Kazak A.E., 2006, p. 561.*

Author Surname	Study key characteristics	Intervention contents	Intervention modes	Outcomes
	2. Substance Abuse and Mental Health Services Administration (SAMHSA).	Trauma informed approach and trauma-specific interventions website: https://store.samhsa.gov/product/practical-guide-implementing-trauma informed-approach/pep23-06-05-005	-	-
	3. National Child Traumatic Stress Network.	https://www.nctsn.org/resources/creating-trauma informed-systems	-	-
	4. Fallot and Harris (2008).	https://nhchc.org/wp-content/uploads/2020/01/Chapter-1-Harris-Fallot.pdf	-	-
Kazak A.E., Alderfer M., et.al. (2004)	Randomised Clinical Trial 150 adolescent cancer survivors (range of cancer diagnosis), 146 mothers and 103 fathers.[87]	Participants completed: IES-R (Weiss & Marmar 1997) 22 item assessment for PTSD; intrusive thoughts, avoidance and hyperarousal, items were assessed on frequency of occurance in the past 7 days. PTSD-RI (Pynoos, Frederick, Nader & Arroyo 1987) 20 item self report measure to identify mild / moderate / severe PTSD.	Survey Survey	Moderate to severe levels of PTSS on PTSD- RI – mothers (43.7%) fathers (35.3%) and teen survivors (17.6%). 29.5% of mothers and 11.5% of fathers met the criteria for PTSD diagnosis.
Kazak A.E. & Boeving A.C., et.al. (2005)	119 mothers and 52 fathers of children in cancer treatment.	PTSD-RI Questionnaire IES-R Questionnaire Intensity of treatment rating scale (Oncologist assessed)	Questionnaires completed + 1 month post traumatic event.[88]	All bar one parent indicated scores consistent with mild PTSS. 68% of mothers and 57% of father reported moderate to severe PTSS. 79.2% of all participating families had one parent with moderate to severe PTSS. PTSS appears to be a common way of responding and adapting to the circumstance. Experiences that are relatively common place in medical settings are frequently experienced as traumatic by parents. Psychosocial care can be targeted to those who are most at risk.

[88] *Diagnostic criteria for PTSD require individuals be at least one month post-traumatic event.*

Author Surname	Study key characteristics	Intervention contents	Intervention modes	Outcomes
Kazak A.E. & Kassam-Adams N. et.al. (2006)	PMTS model is presented. It has 3 stages (i) peritrauma, (ii) early, ongoing and evolving responses, (iii) longer-term.	There are 5 assumptions that underly the model: 1. Potentially traumatic medical events have comorbidities that cut across illness or injury groups. 2. There is a range of normative reactions to medical traumatic events. 3. Patients and families have a range of preexisting psychological functioning. 4. A developmental lens on trauma is essential. 5. A social ecological or contextual approach is optimal for intervention	-	PMTS affects not only paediatric patients but also their families, healthcare teams, schools and communities A traumatic stress model is consistent with research showing that it is the individual's subjective experience of trauma which shapes adult psychological and health outcomes.
Kazak A.E. (2006)	A biopsychosocial framework for assessing and treating the families of children who are in care.	PPPHM is a 3 tier model that identifies Universal, Targeted and Clinical Treatment levels that prompt a targeted intervention. Universal -families who are experiencing distress but otherwise coping well with the onset of paediatric illness Targeted – families who present with factors that predispose them to ongoing difficulties. Their coping skills are likely to be overwhelmed. Clinical Treatment – present with elevated or persistent anxiety or depressant symptoms. Require the most intensive treatment.	Universal – support the competence of these families. Targeted – services required may be located in multiples places eg. clinics and hospital. Clinical – Will likely require multiple hospital-based healthcare teams to support.	
Kazak A.E., Rourke M.T, et.al. (2007)	2 models helpful at conceptualising and standardising clinical care at the Children's Hospital or Philadelphia are summarised. The 2 models are: PPPHM (Kazak 2006) and PMTS (Kazak Kassam-Adams 2006)	PPPHM model that directs the provision of both broad and targeted interventions, differentially based on patient risk. PMTS Model conceptualises traumatic experience across the cancer journey, expressed in 3 stages; peritrauma, early ongoing and evolving responses, and long-term. The models were blended to create a Blueprint for Psychosocial care in paediatric oncology.		The authors recognise that "translating research into practice is an iterative process". The model proposes to assist multi-disciplinary teams to advance practice in paediatric oncology."

Author Surname	Study key characteristics	Intervention contents	Intervention modes	Outcomes
Garcia E. et.al. (2017)	FOCUS model case study. (Families Overcoming Under Stress (FOCUS). Paediatric cancer treatment represents heightened psychological health risk for families. For ethnic minority family's acculturation and language adds complexity, exacerbating experience and subsequently ability to cope and function. Required diversified staff recruitment (including psychologists).	Embedding psychologists in Outpatient paediatric oncology clinic to provide consultations directly to families Key tenets of the model: (a) Completion of real-time behavioural health assessment (b) Provision of psychoeducational and developmental guidance (c) Create of narrative timelines. (d) Development of family resilience skills Each intervention is delivered by staff in the patient's language to ensure synergy with the patient's emotional experience.	Psychologist available in the Oncology Clinic. 8 sessions, 60-90mins each. FOCUS is presented as 'skills training' for the family.	Paper did not describe outcomes in very much detail.
Dhawan N. & LeBlanc T.W. (2022)	Application of TIC to Hematologic Malignancies using SAMSHA framework. Addresses the application of TIC to the clinical setting.	Paper contains a table that describes 19 recommended actions for a Haematologist to take to apply TIC to the clinical setting.	One to one between clinician and patient.	Recommendation made, no results data.

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