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Giving Children a Voice: Children's Perceptions of Pain and Pain  
Management within the Paediatric Emergency Department

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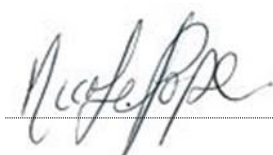
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## Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number #HR46/2015 and the Princess Margaret Hospital for Children Human Research Ethics Committee #2014082EP.

A handwritten signature in black ink, appearing to read 'Nicole Pope', is written above a horizontal line.

**Nicole Pope**

1 May 2018

## **Abstract**

Pain and its management is a major aspect of care provided within the emergency department (ED). Despite a commitment by healthcare professionals to adequately manage pain, effective pain management for children within the ED remains challenging. Given that unrelieved pain in children is linked to a number of negative short and long term physiological, psychological and behavioural consequences, optimal management of children's pain is essential. Compared with adults, research exploring children's views on pain and pain management is limited. Many studies examining children's pain within EDs have adopted quantitative methods and/or sought the perspectives of adults. While results of these studies have made important contributions to our understanding and management of children's pain, these approaches risk missing the entire pain experience from the children's perspective. A better understanding of children's pain relies upon research inquiry that respects the capacity of children to express rich and trustworthy accounts of their experiences.

This qualitative study explored children's (aged four to eight years) acute pain experiences within the ED of a tertiary paediatric hospital in Western Australia. The aim of this study was addressed through three objectives. Firstly, to explore children's perceptions of their acute pain while in the ED; secondly their perceptions of the pain management they received while in the ED, and finally their perceptions of the role of the nurse in helping children who have pain.

A qualitative descriptive design offered an inductive approach to explore children's experiences. Fifteen children (11 males and four females, aged four to eight years) who presented to the ED with acute pain agreed to participate in the study. Data were collected using the draw, write and tell (DWT) technique. In line with the DWT process, children were asked to draw a picture(s) which represented their pain. Children were then invited to write words, and verbally describe to the researcher what they have drawn. These narratives were audio recorded and transcribed, and subjected to thematic analysis as described by Braun and Clarke (2006). The drawings were not subject to analysis. Throughout data collection and analysis field notes, reflexive notes, and a decision-making trail were maintained by the researcher and discussed with the research team.

Three main themes emerged; 1) 'Security', 2) 'My pain' and 3) 'Comfort and relief', which contributed to a conceptual framework. The theme 'My pain' included two subthemes, 'The pain feelings' and 'My sad/happy feelings'. The theme 'Comfort and relief' included three subthemes named, 'Hospital things', 'Taking my mind off it' and 'Resting'. While the two themes 'My pain' and 'Comfort and relief' were reliant on the theme 'Security', both were found to be independent of each other.

When in pain children needed to feel secure to share their pain experiences with others and identify strategies that helped them when they had pain. Parents and nurses were important in fostering this sense of security for children. Children were capable of describing their pain which extended beyond physical dimensions to include emotional, visual and sensory features. Children also identified a range of non-pharmacological strategies that helped them when in pain. However, none of this was possible without feeling secure.

Findings from this study emphasise the need to foster a sense of security for children attending the healthcare setting in pain. When children feel secure, they are able to express their pain and pain needs openly. Feeling secure also offers a form of comfort for children. The presence and nurturing actions of primary caregivers are important to provide the feeling of security. In addition, nurses who listen, who are honest, and who develop a trusting rapport with children are helpful. Nurses need to enable and encourage children to provide detailed accounts of their pain and pain needs. As well as inquiring about physical aspects of their pain, nurses should ask children about the psychosocial dimension of their pain. Greater attention to the therapeutic use of non-pharmacological strategies is necessary by supporting children to engage in activities they enjoy to distract from their pain. In addition to listening to primary caregivers, appreciating that children are capable of being actively involved in their pain management is essential. Acknowledging children's capability can lead to inclusion in decision making related to their care. This is key to effective pain management for children.

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## Publications, Presentations and Awards

### Publications

- 2018** Pope, N., Tallon, M., Leslie, G., Wilson, S. (in press). Ask me: Children’s experiences of pain explored using the draw, write and tell method. *Journal for Specialists in Pediatric Nursing*
- 2017** Pope, N., Tallon, M., Leslie, G., Wilson, S. (2018). Using ‘draw, write and tell’ to understand children’s health related experiences: Learning with children through research. *Nurse Researcher*, 29 (2) DOI: 10.7748/nr2018.e1594
- 2017** Pope, N., Tallon, M., Leslie, G., Wilson, S. (2017). Editorial. Why we need to research with children, not on children. *JBIR Database of Systematic Reviews and Implementation Reports*, 15(6), 1497-1498. DOI: 10.11124/jbisrir-2017-003458
- 2017** Pope, N., Tallon, M., McConigley, R., Leslie, G., & Wilson, S. (2017). The experiences of acute pain of children who present to a healthcare facility for treatment: a systematic review of qualitative evidence. *JBIR Database of Systematic Reviews & Implementation Reports*, 6 (15), 1612–1644. DOI: 10.11124/JBISRIR-2016-003029
- 2015** Pope, N., Tallon, M., McConigley, R., & Wilson, S. (2015). The experiences of acute non-surgical pain of children who present to a healthcare facility for treatment: a systematic review protocol. *JBIR Database of Systematic Reviews & Implementation Reports*, 13 (10), 12-20. DOI: 10.11124/jbisrir-2015-2466

## **Presentations**

### *Peer reviewed*

- 2017** Poster Presentation: Child and Adolescent Health Service Research Symposium, Perth, Western Australia: Children's experiences of pain explored using Draw, Write and Tell.
- 2016** Poster presentation: The Australian College of Children and Young People's Nurses Conference, Adelaide, South Australia: Children's Experiences of Acute Pain within a Healthcare Facility: A Systematic Review.
- 2016** Oral Presentation: Australian Pain Society 36th annual scientific meeting, Perth, Western Australia: Giving children a voice: Children's perceptions of pain and pain management within the paediatric emergency department.

### *By invitation*

- 2017** Oral Presentation: Mark Liveris Conference, Curtin University, Perth, Western Australia: Children's experiences of pain explored using Draw, Write and Tell.
- 2017** Oral Presentation: Princess Margaret Hospital for Children post graduate nurses Community of Practice: Perth, Western Australia: Children's experiences of pain and pain management within the emergency department.
- 2017** Oral Presentation: Higher Degree by Research Seminar, Curtin University, Perth, Western Australia: Children's experiences of pain within a healthcare facility: A systematic review.
- 2016** Oral Presentation: Mark Liveris Conference, Curtin University, Perth, Western Australia: Children's perceptions of pain and pain management within the emergency department: Preliminary findings using the draw, write and tell technique.

**2015** Oral Presentation: Visual Research Methods Symposium, Curtin University, Perth, Western Australia. Giving children a voice: Children's perceptions of pain and pain management within the paediatric emergency department.

### **Awards**

**2017** Best Presentation Award: Mark Liveris Conference, Curtin University, Perth, Western Australia: Children's experiences of pain explored using draw, write and tell.

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# Chapter 1 Introduction

*‘Children should in all circumstances be among the first to receive protection and relief, and should be protected from all forms of neglect, cruelty and exploitation’*

(United Nations, 1989)

## 1.1 Background

The International Association for the Study of Pain defines pain as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage’ (Lindblom et al., 1986, p. S217) which emphasises the physical and emotional nature of pain. Pain is a multifaceted phenomenon which includes physiological, sensory, cognitive, affective, spiritual and behavioural dimensions (World Health Organisation, 2012). Importantly, pain is among the most frequent symptoms associated with emergency department (ED) presentations (Crellin et al., 2017; Herd, Babl, Gilhotra, & Huckson, 2009; Scott, Crilly, Chaboyer, & Jessup, 2013). In 2015–16, over 7.5 million presentations were made to public EDs across Australia. Children under 15 years of age represented 22 percent of these (Australian Institute of Health and Welfare, 2016). Although some EDs have well defined pain management protocols and guidelines, evidence repeatedly suggests that pain management within EDs remains suboptimal and inconsistent, particularly for paediatric patients (Bailey, Gravel, & Daoust, 2012; Crocker, Higginbotham, King, Taylor, & Milling, 2012; Drendel, Brousseau, & Gorelick, 2006; Scott et al., 2013).

Like many clinical settings, the ED of a Western Australian (WA) tertiary paediatric hospital has a number of clinical guidelines governing pain management including: recommendations for pharmacological and non-pharmacological management of pain for children presenting with mild to moderate, or moderate to severe pain; nurse-initiated analgesia; and drug specific protocols. Despite this, a hospital wide audit of case notes showed that there was less than 60 per cent compliance with pain score documentation (O’Loughlin & Corkish 2013). Similar findings have been reported in national (Babl et al., 2012; Scott et al., 2013) and international studies (Downey & Zun, 2012; Drendel,

Kelly, & Ali, 2011) examining paediatric pain management practices, where pain scores and the effectiveness of analgesia are not well documented. However, evidence suggests that poor documentation does not necessarily equate to poor pain management (Kaplan, Sison, & Platt, 2008). Therefore, results of this hospital audit may not accurately reflect the effectiveness of pain management.

## **1.2 Children's perceptions of their pain experience**

Over the past two decades there has been growing recognition among researchers of the importance of including children's experiences using qualitative inquiry as a way to better understand their pain and pain needs. In 2013 a systematic review of qualitative evidence was undertaken to explore children's experiences of their post-operative pain management. While findings indicated that children (4-18 years old) were able to express their pain and identify the role of analgesia in managing their pain, they also emphasised the role of primary caregivers and healthcare professionals in implementing non-pharmacological interventions to help with their pain (Wen, Taylor, Lixia, & Hong-Gu, 2013). These findings draw attention to effective pain management approaches when caring for children in the post-operative period.

Similarly, a study from the United Kingdom adopted a mixed methods approach to gain insight into the post-operative pain experience of children. This study was not included in the systematic review by Wen et. al. (2013). During the study interviews were undertaken with children (n=8) while parents (n=10) completed a questionnaire to provide their perceptions of their child's pain management. Despite parents and children being satisfied with care overall, the results indicated that post-operative pain management was suboptimal (Twycross & Finley, 2013). These results must be interpreted with caution as participants were still inpatients during the interviews and may have withheld negative comments to avoid any impact on the care provided.

Another United Kingdom study adopted a qualitative descriptive design using the draw and write technique to investigate children's views on what helped when they were in pain. The children (n=71) were between four and 16 years of age. Findings revealed that children viewed themselves as active agents in pain management, but also identified that primary caregivers and nurses played an important role in helping them when they had pain (Franck, Sheikh, & Oulton, 2008).

These studies highlight that involving children as participants in research can contribute to a better understanding of their pain experiences. Effective pain management for children is an essential part of paediatric healthcare, however children continue to needlessly experience pain while in hospital (Harrison et al., 2014; Simons, 2015; Ullán et al., 2014).

### **1.3 Context of the Study**

Healthcare for Australian residents is provided under a universal public health insurance scheme called Medicare, which provides free or subsidised access to public hospital services and treatment (Australian Institute of Health and Welfare, 2017b). In addition to hospital services, Medicare also funds and subsidises medical and pharmaceutical services. Medicare funding is provided through a mix of state and federal taxes and offers public patients in public hospitals healthcare services at no out of pocket expense (Australian Institute of Health and Welfare, 2016a). Although hospitals can be private or publicly funded, the majority are public, and few private hospitals include EDs.

Australian public hospitals provide a range of healthcare services including acute, subacute and non-acute services to admitted patients, emergency and outpatient services to non-admitted patients and mental health and public health services. While many of Australia's larger public hospitals have a paediatric ward and mixed EDs (catering for children and adults), there are also several Australian Paediatric hospitals which cater specifically to the care of children and their families. In Australian public hospitals, healthcare services are provided by a range of healthcare professionals including medical practitioners, nurses, nurse practitioners, and allied health (i.e. physiotherapists, occupational therapists, social workers).

This study was conducted in the ED of the only Western Australian, public tertiary paediatric hospital, Princess Margaret Hospital for Children (PMH). This paediatric facility has a capacity of 220 inpatient beds and provides care to children and adolescents aged zero to 16 years. In 2017 Western Australia had a population of 2.57 million and an annual growth rate of 0.7 per cent (Australian Bureau of Statistics, 2017). Princess Margaret Hospital for Children treats up to 250,000 patients each year, while the ED sees over 65,000 presentations annually (Australian Institute of Health and Welfare, 2016b).

Children may present to ED at any time via ambulance, or with a primary caregiver by their own means. On presentation to ED, children are assessed by the triage nurse and assigned a category following the Australasian Triage Scale (ATS). Categories range from 1 to 5, ensuring that children are seen in a timely manner, commensurate with their clinical urgency. The ATS includes an assessment and documentation of pain which is undertaken by the triage nurse (Hodge, Hugman, Varndell, & Howes, 2013). Children are then assessed by an ED nurse and doctor, and medical treatment is initiated as required. Hospital guidelines recommend that non-pharmacological pain relieving strategies are initiated by the triage nurse, and pain relief medications are prescribed by an ED doctor or nurse practitioner. Nurse initiated analgesia can be administered by nurses who are adequately trained to do so but are limited to non-prescription (over-the-counter) medications. All other pain relief medications are prescribed by a medical practitioner and in most cases administered by a nurse (Australian Commission on Safety and Quality in Health Care, 2014).

#### **1.4 Statement of Problem**

Despite a commitment among healthcare professionals, research shows that children continue to needlessly experience pain as a result of ineffective pain management practices (Harrison et al., 2014; Stevens et al., 2012; Twycross et al., 2016; World Health Organisation, 2012). This is particularly so in ED settings (Ortiz, López-Zarco, & Arreola-Bautista, 2012; Scott, Crilly, Chaboyer, & Jessup, 2013). Studies examining children's views on pain management are limited compared with adults. Much of the evidence related to children's pain experience in EDs has come from quantitative research (Herd et al., 2009; Scott et al., 2013), or sought the perspectives of adults such as primary caregivers or healthcare professionals (Ali et al., 2015; Thomas et al., 2015). While these methods contribute to our understanding and management of children's pain, results do not capture the entire pain experience from the children's perspectives. Inadequately managed pain in children impacts their quality of life and has been linked to several negative short and long term physical and psychological consequences. Effective pain management is therefore a priority area for healthcare professionals.

Qualitative studies examining children's pain have been undertaken in paediatric hospitals mostly in Europe, Asia and North America. However, an extensive search of



the literature found few published qualitative studies undertaken in paediatric EDs and failed to find any studies examining children's perspectives in an Australian ED setting.

### **1.5 Aim and Objectives**

The primary aim of this study was to explore children's (aged four to eight years) perceptions of acute pain and pain management provided while in the ED of a Western Australian tertiary paediatric hospital. The specific objectives to meet this study's aim were to explore children's perceptions of:

1. their pain while in the ED
2. their pain management provided while in the ED
3. the role of the nurse in pain management.

### **1.6 Significance of the Study**

This study was the first to explore children's experiences of acute pain and pain management within the ED using a participatory research approach. The results have implications for children in ED who have acute pain. Gaining insight into children's needs and expectations when they have pain may lead to improved pain management within the ED and optimise health outcomes for children and their families. Furthermore, gaining a deeper understanding of children's pain experiences from their perspectives embraces the philosophy of partnership in care, central to paediatric nursing practice.

### **1.7 Operational Definitions and Abbreviations**

The following descriptions define some of the terminology and abbreviations used in this thesis:

- a. A *young child* is defined as a person aged between one and eight years.
- b. An *older child* is defined as a person aged between nine and seventeen years.
- c. A *child* is defined as a person who is aged between one and seventeen years.
- d. Defined in keeping with Australian Resuscitation Council (2014)

- e. A *healthcare professional* is defined as a person who provides any form of healthcare service to patients. Examples are nurses, nurse practitioners, physiotherapists and medical doctors.
- f. A *primary caregiver* is defined as a person who takes primary responsibility for care of a child who cannot fully care for themselves. Examples are parents, grandparents, foster parents, guardians and other relatives or carers.
- g. *DWT (Draw, write and tell)*: A participatory research technique used in undertaking the qualitative study.
- h. *ED (Emergency department)*: A unit of a hospital where patients can present with medical concerns by their own means or by ambulance at any time without prior appointment.
- i. *GCT (Gate control theory)*: A theory of pain put forward by Ron Melzack and Patrick Wall in 1965 addressing how and why pain is perceived in humans.
- j. *HREC (Human research ethics committee)*: A committee which reviews research proposals involving human participants to ensure that they are ethically acceptable and in line with relevant standards and guidelines.
- k. *JB I (Joanna Briggs Institute)*: An international research and development centre which focuses on promoting and supporting the synthesis, transfer and utilisation of evidence to assist in the improvement of healthcare outcomes.
- l. *PMH (Princess Margaret Hospital for Children)*: A tertiary paediatric hospital located in Perth, Western Australia.
- m. *SR (Systematic review)*: Literature that collects and analyses multiple research studies to produce meta-synthesised findings.

## **1.8 Overview of Thesis**

This thesis is presented in seven chapters. Three of these chapters are manuscripts that have been accepted for publication in international peer-reviewed journals. Presentation of each manuscript is in line with each journal's copyright policy.

Following this introduction, Chapter 2 provides the background which includes an outline of the complex, multifaceted nature of pain and approaches to pain management, including assessment and interventions. The importance of involving children collaboratively in research to better understand their pain is also examined.

Chapter 3 contains a systematic review (SR) of qualitative evidence examining children's perceptions of acute pain and pain management within a healthcare

facility. This manuscript was published in the Joanna Briggs Institute Database of Systematic Reviews & Implementation Reports. The synthesis of findings from the qualitative studies contributed to the knowledge in this area and informed the background to this study.

Chapter 4 describes the method used for the primary qualitative study undertaken to meet the study objectives and describes the application of the DWT technique to explore children's pain in ED. Aspects of the study design including the study setting, sampling approach and data collection are explained. Data analysis is discussed, and ethical considerations presented.

The challenges and benefits of engaging children in research using draw, write and tell (DWT) within a participatory research framework, are discussed in Chapter 5. The chapter is a copy of the manuscript published in the peer reviewed journal, Nurse Researcher.

Results of the qualitative study are presented in Chapter 6 in the form of a manuscript accepted for publication in the Journal for Specialists in Pediatric Nursing. As it is a copy of the original manuscript there is some repetition of the methods presented in Chapter 4.

To conclude the thesis, in Chapter 7 findings from the qualitative study are discussed within the context of the literature and in relation to the three specific study objectives. Finally, implications for clinical practice and research are offered.

## Chapter 2 Background

Pain is subjective, personal and multifaceted. This chapter begins by providing an overview of the pain phenomenon, focussing on the evolution of our understanding of pain over the last five decades. The consequences of unmanaged pain in children that leads to children's pain management as a public health priority follow. Approaches to the comprehensive assessment of children's pain are described with consideration for self-report, behavioural observations, and physiological measures. Several pain assessment models are introduced. Pharmacological and non-pharmacological strategies as interventions for acute pain are presented. Finally, the importance of research that examines children's perspectives of pain is considered.

### 2.1 Pain: A Multifaceted Phenomenon

Pain has an important function as a warning mechanism to protect us from harm (Bentley, 2013), and can be defined as acute (a time limited response to a painful stimuli) or chronic (persisting for beyond three months) (Pain Australia, 2011). As with adults, children's pain is a subjective, multifaceted phenomenon which extends beyond the physiological interpretation of a noxious stimulus to include sensory, cognitive, affective, spiritual and behavioural dimensions (World Health Organisation, 2012). This understanding of pain is the result of a long history of research examining the pain phenomenon.

The traditional theory of pain, Specificity Theory, formulated by Schiff in 1858, conceived the system of pain as a direct channel, independent of touch and other sensors, from injured tissues to the brain (Moayedi & Davis, 2013). The Gate Control Theory (GCT) (Melzack & Wall, 1965) grew out of Specificity Theory to integrate both psychological and physiological dimensions of pain modulation. The GCT proposes that the transmission of nerve impulses from nociceptive receptors via small diameter nerve fibres to the brain are regulated by a gating mechanism influenced by the stimulation of large diameter nerve fibres that block the transmission of these pain impulses within the spinal dorsal horn. Activity in large diameter nerve fibres closes the gate. When the gate is closed transmission of pain impulses from pain receptors via the small nerve fibres is blocked and pain is reduced. Activity in small diameter nerve fibres opens the gate

allowing transmission of impulses and painful sensations to be perceived. Nerve impulses that descend from the higher centres in the brain (thalamus, hypothalamus and cortex) also play a part in keeping the gate closed. This emphasises the dynamic role of the nervous system in pain modulation (Melzack, 1996).

While the GCT remains useful in understanding pain, the Neuromatrix Theory also proposed by Melzack (1999) suggests that the processes for interpreting and responding to pain are best understood as a network of areas in the brain that interact with each other and with the spinal cord's gating mechanism. According to this theory, the level of attention paid to the pain, the emotions associated with pain, as well as memory and arousal states, influence how a person's pain is interpreted and experienced (Melzack, 1999).

Alongside this development in thinking, the past 50 years has seen clinical research make revolutionary contributions to our understanding of paediatric pain. The premise that infants do not physiologically experience pain the same way as adults, and that children "won't remember" their pain have been rejected. Early misconceptions that infants did not perceive pain due to underdeveloped neurological structures (McGraw, 1943), perpetuated the neglect of pain treatment for infants until the 1970s (Pillai Riddell et al., 2015). In the 1980's a better understanding of pain perception in infants was endorsed by evidence confirming that neural structures associated with processing and interpreting pain are formed during early fetal development, and that newborns have fully functioning anatomical components required for the perception of painful stimuli (Anand & Hickey, 1987). More recent research has highlighted the impact of this and has also found that early repetitive neonatal pain experiences are linked with poor developmental outcomes for children (Valeri et al., 2014). In affected children, these early experiences impact their responses, behaviours and perceptions during future experiences of pain (Noel, Rabbitts, Fales, Chorney, & Palermo, 2017).

Other factors that influence a child's pain experience include their age, cultural background, cognitive development, temperament, personality and family learning (Twycross & Williams, 2013). These psychosocial dimensions of pain contribute to our understanding of how, the absence of a primary caregiver, being in an unfamiliar environment, and emotions like fear and anxiety may be more distressing to a child than the physical symptoms of pain (Wen et al., 2013) further exacerbating the severity

of their pain (LeMay et al., 2010; Ortiz, López-Zarco, & Arreola-Bautista, 2012). Further to the absence of primary caregivers(s), evidence shows that the way primary caregivers respond to their child's pain can negatively influence the child's pain experience (Vervoort, Trost, & Van Ryckeghem, 2013). For instance, parental catastrophising, comprising elements of rumination, magnification, and helplessness, can exacerbate a child's response to their pain (Hechler et al., 2011).

While our understanding of pain has evolved in the last 50 years and the presence of evidence-based guidelines on pain assessment and interventions, effective pain management for children remains a significant clinical challenge (Crellin et al., 2017; Harrison et al., 2014; Herd et al., 2009; International Association for the Study of Pain, 2010; Pillai Riddell et al., 2015; Shomaker, Dutton, & Mark, 2015; Wen et al., 2013; World Health Organisation, 2012; Shomaker, Dutton, & Mark, 2015; Wen et al., 2013). Unrelieved pain can have serious implications across a child's lifespan and is linked to a number of short and long-term physiological and psychological outcomes (Pain Australia, 2011).

Evidence shows that poorly managed pain is associated with an increase in sensitivity to pain, (Farahani, Alhani, & Mohammadi, 2013), reduced functioning, sleep disturbances and delayed recovery (Williams et al., 2015). Further, mismanaged pain is a known risk factor for chronic pain (Purser, Warfield, & Richardson, 2014; Williams et al., 2015). In addition to these physiological consequences, psychosocial costs of poorly managed pain include increased anxiety and distress, fear of healthcare professionals, later avoidance of medical care (Harrison et al., 2015) and in extreme cases leads to medical traumatic stress and depression (Rzucidlo & Campbell, 2009). Moreover, the broader consequences of poorly managed pain include significant direct and indirect costs for families, healthcare, and society (Pain Australia, 2011; Purser et al., 2014).

Managing pain in children is also an ethical imperative highlighted by the United Nations in their Declaration on the Rights of the Child (United Nations, 1989). More recently, the Declaration of Montreal, outlined five human rights in relation to pain and its management: 1) the right to indiscriminate access to pain management, 2) the right to be informed about how their pain can be assessed and treated, 3) the right to have appropriate pain relief medications, 4) the right assessment and treatment by

appropriately trained healthcare professionals, and 5) the right to access non-pharmacological pain relieving interventions (International Association for The Study of Pain, 2011, p. 29). Although not specific to children, these rights were written inclusive of all ages and to guide healthcare professional's caring for people in pain.

The rights incorporate assessment and interventions which are consistent with the 'gold standard' for managing pain developed by the American Nurses Association; a three step process known as the pain assessment-intervention-reassessment (AIR) cycle (Lacey, Klaus, Smith, Cox, & Dunton, 2006). The AIR cycle is included in the National Database of Nursing Quality Indicators (NDNQI®) and involves: 1) assessing pain, 2) providing pain relief interventions (pharmacological and non-pharmacological), and 3) reassessing the effectiveness and any side-effects of pain relief interventions. As indicated in the AIR cycle, effective pain treatment is contingent on assessment that occurs at regular intervals.

## **2.2 Assessing Children's Pain**

The first step in effective pain management is adequate pain assessment. In clinical practice pain assessment is now widely considered to be the 'fifth vital sign' (International Association for the Study of Pain, 2010), emphasising that pain should be routinely assessed with the other four vital signs which are temperature, pulse, respiratory rate and blood pressure (Farahani et al., 2013). Alongside obtaining a detailed pain history and undertaking a physical examination, the measurement of pain severity is assessed by self-report, behaviour observations, and/or physiological measurements (Tomlinson, von Baeyer, Stinson, & Sung, 2010). Self-report is often viewed as the most reliable method of pain assessment (International Association for the Study of Pain, 2005; Tomlinson et al., 2010).

Over the last two decades there have been considerable efforts among researchers and clinicians devoted to the development of paediatric pain assessment tools to quantify children's pain. The complex nature of testing reliability, feasibility and validity of tools are acknowledged. Despite these challenges, important advances included the development of a range of scales using sketches of faces as self-report pain assessment tools, which have been validated and used in paediatric healthcare facilities internationally (Tomlinson et al., 2010; Tsze, Von Baeyer, Bulloch, & Dayan, 2013).

Faces pain scales such as the Oucher (Beyer & Aradine, 1986), Wong-Baker FACES Pain Scale (Wong & Baker, 1988), and the Faces Pain Scale-Revised (FPS-R) (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2000) are widely used self-report pain scales with psychometric properties reported that support their validity and clinical utility in paediatric pain assessment (Tomlinson et al., 2010). While these scales vary slightly, each consists of a series of facial expressions arranged horizontally that represent different levels of pain intensity. The child is asked to select a face that best represents their pain. Because these tools do not rely on the understanding of words or numerical scales they are validated for use by children aged four to 16 years old (Drendel et al., 2011). Faces pain scales with neutral expressions for 'no pain', such as the FPS-R are recommended over those with happy or smiling faces for 'no pain', for example the Wong-Baker FACES Pain Scale, as these have been found to produce higher pain ratings than scales with neutral expressions (Stinson & Jibb, 2013). Self-report tools are not recommended in children whose cognitive development renders them unable to follow through with the task (Tomlinson et al., 2010).

For older children, as with adults, another method of self-report involves asking the person to rate the severity of their pain on a numerical scale (from 0 indicating no pain to 10 indicating worst pain). To support younger children's understanding, self-report pain assessment tools that incorporate graphic representation of the numerical scale, such as the Visual Analog Scale (VAS), are often used (Bailey et al., 2012). The VAS, which is validated for use in adults and children eight years or older (Stinson & Jibb, 2013), consists of a 100mm horizontal line where the endpoints of the line define extreme limits (i.e. no pain versus worst possible pain). The child is asked to mark on the horizontal line to indicate the severity of their pain.

The assessment of pain for children of all ages who are unable to self-report, including some children with cognitive impairment, relies on pain assessment tools that report behaviour observations. These tools require the healthcare professional to observe the child for behavioural cues reliably associated with pain (i.e. cry, withdrawal of affected limb, and facial expressions) (Arif-Rahu, Fisher, & Matsuda, 2012). Each behaviour is scored according to the tool, the cumulative total indicating the pain severity. The Faces, Legs, Activity, Cry, Consolability (FLACC) scale (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997) and COMFORT (Ambuel, Hamlett, Marz, & Blumer, 1992) are examples of behaviour observation tools. These rely on the expression and



body language of the patient, and the interpretation of the healthcare professional. A child can self-report on the behaviour pain scales, but the score should be validated by the child self-reporting using the VAS or a faces pain scale if they are able (Arif-Rahu et al., 2012).

Used in combination with self-report and behaviour observation measures, physiological measurements involve monitoring the child for indicators elicited in the stress response (e.g. tachycardia, tachypnoea, hypertension, and pupil dilation) which are commonly associated with pain. The use of physiological measures in the assessment of pain has been debated given the lack of specificity for pain, therefore it is recommended that these measures be used with caution and in conjunction with other validated pain assessment tools (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Absence of a change in physiological indicators is not a reliable sign of the absence of pain.

Reports about a child's pain offered by primary caregivers and family members are also important in the assessment of pain as they are likely to have detailed knowledge of the child's usual behaviours and can identify subtle changes that may indicate the child has pain (Herr et al., 2011). However, evidence has shown that discrepancies exist between a child's self-report of pain and assessments made by other people, with healthcare professionals underestimating and primary-caregivers overestimating the intensity of pain (Herr et al., 2011; Schiavenato & Craig, 2010)

While the availability of valid and reliable pain assessment tools is central to pain management, it has been argued that pain assessment scores alone do not do justice to the multifaceted pain phenomena, and these assessment approaches neglect features such as sensory qualities, as well as emotional and cognitive dimensions of pain (Schiavenato & Craig, 2010). The complex interplay between the patient and clinician during pain assessment also requires consideration (Schiavenato & Craig, 2010).

### **Models of assessment of children's pain**

The dynamic interaction between physiological, psychological, and societal factors that influence a person's experience of pain are considered in The Bio-behavioural Model of Paediatric Pain developed by Varni (1995). This biopsychosocial model of pain assessment emphasises how psychosocial factors such as stress, anxiety and

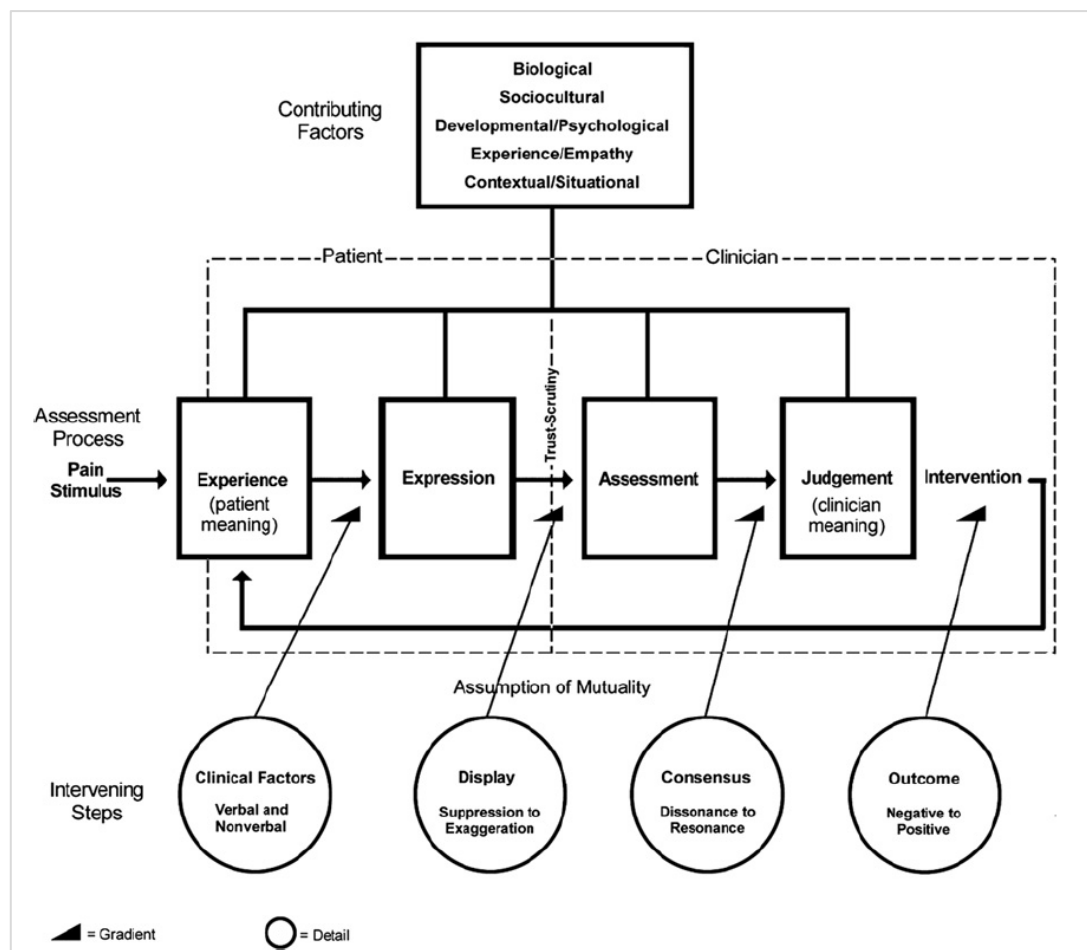
depression, as well as relationships with primary caregivers and peers can influence a child's pain perception and pain behaviours (Varni, 1995). While biopsychosocial models such as Varni's (1995) are widely acknowledged and appraised for use in the assessment and interventions of children with chronic pain (Vetter, McGwin, Bridgewater, Madan-Swain, & Ascherman, 2013; White & Farrell, 2006), there is less of an emphasis on the use of these models in children with acute pain.

Similarly, the Social Communications Model provides a framework that considers the interplay between biological, psychological, and social determinants of pain assessment (Craig, 2009). This three-step model emphasises verbal (e.g. self-report) and non-verbal (e.g. facial expression) communication, and the social context in which pain is experienced, assessed and subsequently managed. The first step begins with the patient's internal experience of pain, which is then encoded as a result of automatic and higher mental processing in self-report and behavioural expression. The second step, draws attention to the factors that influence the expression of pain accounting for developmental stage and cognitive capacity. Following this the assessor (healthcare professional) decodes the cues, whereby complexities of interpersonal judgement and observer bias are considered (Craig, 2009). This model is applicable to acute and chronic pain and contributes to the overall discussion on the assessment of pain in children.

Children's pain as a multifaceted phenomenon is also considered within the pain assessment as a transaction (PAST) model (Schiavenato & Craig, 2010). As with the two models discussed earlier, this model depicts the complex and dynamic social transaction between the patient and healthcare professional in pain assessment. The PAST model is applicable and advocated in pain management for children (Voepel-Lewis, Piscotty, Annis, & Kalisch, 2012). This model comprises of three components; 1) 'Contributing Factors', 2) 'The Assessment Process', and 3) 'Intervening Steps' (Schiavenato & Craig, 2010, p. 670) (See Figure 2.1).

As suggested in the PAST model, several factors mediate the process of pain assessment, and are related to both the healthcare professional and patient. These are termed contributing factors (Figure 2.1) and emphasise the interpersonal and intrapersonal domains that influence pain assessment. From a patient's perspective, sociocultural factors (e.g. ethnicity, language, healthcare access, social roles/relationships) are widely implicated in pain assessment (Finley, Kristjansdottir,

& Forgeron, 2009; Nortje & Albertyn, 2015). While literature related to how sociocultural factors effect pain assessment from the healthcare professionals' perspective is scarce, the underpinning principle of the PAST model suggests that sociocultural factors also influence the healthcare professional's interpretation of pain, and how they conduct the pain assessment (Schiavenato & Craig, 2010).



**Figure 2.1 Pain assessment as a transaction**

From Schiavenato M, Craig K. Pain as a social transaction beyond the “gold standard.” *Clinical Journal of Pain* 2010; 26:672.

<https://journals.lww.com/clinicalpain/pages/default.aspx>

As seen in the PAST model, other contributing factors to adequacy of pain assessment include experience/empathy and contextual/situational factors. A patient's previous pain and memories have been shown to influence subsequent experiences (Noel et al., 2017), which highlights the cognitive dimension of pain. From a healthcare professional perspective, experience relates to their clinical knowledge, skills and training associated with pain assessment and management. It also draws attention to

the potential influence of repetitive exposure to patients' pain, which can lead to a lack of sensitivity to others' pain (Pillai-Riddell & Craig, 2007). Related to this is the concept of empathy; being sensitive to a patient's pain based on ones' experience, which can be influenced by things such as the way a patient behaves when they have pain, as well as the healthcare professional's beliefs, attitudes and biases which impact dispositions to recognise, understand and treat others' pain (Craig, 2015; Goubert et al., 2005). From a patient's perspective contextual and situational factors include aspects such as communication barriers or other symptoms resulting from pain or treatments such as feeling nauseous or tired (Voepel-Lewis et al., 2012). For the healthcare professional these factors relate to variables such as interdisciplinary communication and staffing (Schiavenato & Craig, 2010).

The assessment process (Figure 2.1) is the second component which begins with the pain stimulus and moves from the patient's personal pain experience to the healthcare professional. Because the healthcare professional's assessment and judgement leads to intervention, the patient's experience is directly impacted by the assessment process. Like the Social Communication Model, the assessment process starts with the patient's subjective experience of pain, which leads to their personal expression of pain. The healthcare professional's perceptions of these pain expressions then guides pain assessment and subsequent intervention (or lack of) (Schiavenato & Craig, 2010). Finally, the third component is the intervening steps (Figure 2.1), these are possible products of each stage that influence the subsequent stage (Voepel-Lewis et al., 2012).

Fundamental assumptions to the PAST model include: 1) Pain is viewed as a dynamic, ongoing process between the patient and healthcare professional and is influenced by external factors; 2) The relationship between the patient and healthcare professional is mutual where the "... patient wants to minimise their pain and that the clinician wants to treat it or alleviate it" (Sammons, Wright, Young, & Farsides, 2016, p. 668). Additionally, the concept of trust and the exchange of meaning between the patient and healthcare professional (and back) influence the way pain is expressed by the patient, and the healthcare professional's assessment of pain. While this model was based on the assessment of pain in adults, others have suggested changes relating to decision making to better fit with a partnership in care and application to children (Voepel-Lewis et al., 2012).

A comprehensive, biopsychosocial assessment is also seen in the “CARES” model, where a bundled approach to pain assessment is proposed with a specific focus on clinical use (Twycross, Voepel-Lewis, Vincent, Franck, & Von Baeyer, 2015). The “CARES” approach emphasises that pain assessment requires a complete assessment in light of four areas; Context (source of pain), Assessment (via self-report and behaviour observation), Risk assessment (physiological factors and response to pharmacological and non-pharmacological treatment), Emotional assessment (consideration of biopsychosocial factors that affect a child’s self-report of pain, and emotional responses to pain) and Sociocultural assessment (understanding care preferences of the child and family). Like the PAST model, the “CARES” approach is advocated in pain management for children (Twycross et al., 2015).

Each of the pain assessment models described above attempt to be inclusive of biological, developmental and psychosocial factors that contribute to the pain phenomenon. Many of these factors are not captured in the pain assessment tools previously described. Further, the models emphasise the influences on the pain assessment process which ultimately influences pain interventions.

### **2.3 Approaches to Pain Interventions for Children**

To address the multifaceted nature of pain, adequate intervention relies on a combination of pharmacological and non-pharmacological strategies such as cognitive-behavioural, physical-sensory, and environmental measures (Pillai Riddell et al., 2015; World Health Organisation, 2012).

Pharmacological strategies involve the use of medications which act in various ways on the nervous system to relieve symptoms of pain. Many clinical practice guidelines and protocols governing the administration of pain relief medication for children are underpinned by the WHO two-step approach to pharmacological pain relief for persistent pain in children. The two-step approach outlines the safe and effective administration of different types of medications based on pain severity and begins with administering paracetamol or ibuprofen (alone or in combination) for the treatment of mild pain. The second step addresses moderate to severe pain and recommends the need for opioid medication beginning with low doses and increasing depending on the severity of pain (World Health Organisation, 2012).

The two step strategy is guided by three principles; 1) administration of pain relief at regular intervals with access to additional ‘rescue doses’ for breakthrough pain when pain is constant, 2) using the appropriate route of administration where oral formulations should be the first-line route, and alternative routes (such as intravenous, subcutaneous, rectal) used based on the child’s clinical needs and personal preferences, and 3) adapting treatment to the individual child where all pain relieving drug doses are based on a child’s weight and/or age as recommended (World Health Organisation, 2012).

While pharmacological measures are important and when administered as per evidence-based recommendations are generally safe for children, there are also known adverse reactions associated with their use. Milder symptoms such as nausea, vomiting, sedation, and constipation are commonly experienced by children following pain relief medication (Hartling et al., 2016). The long-term potential for addiction is lessened with controlled administration of strong pain relief (i.e. opioids) and cases of tolerance and overdose are even rarer (Cooper et al., 2017). However, even mild adverse reactions compound the unpleasantness of pain for children (Woragidpoonpol, Yenbut, Picheansathian, & Klunklin, 2013).

In addition to pharmacological strategies, non-pharmacological therapies are also advocated in managing pain in children (Friedrichsdorf, 2014; World Health Organisation, 2012). In general, non-pharmacological strategies can be classified into three categories; cognitive-behavioural, sensory and environmental measures (Wen et al., 2013; Woragidpoonpol et al., 2013). Cognitive-behavioural methods include engaging children in activities such as playing games, puzzles, reading, listening to music, watching television, drawing pictures, and undertaking relaxation techniques (breathing exercises, imagery, hypnosis) as well as positive self-talk (Twycross & Stinson, 2013; Woragidpoonpol et al., 2013). These methods help children to distract from the pain. The effectiveness of cognitive-behavioural strategies can be explained in terms of the GCT (Melzack & Wall, 1965) where the gate is closed as a result of the child focusing on the distractor, blocking transmission of pain receptors to the brain. As a way to support effectiveness of these cognitive-behavioural strategies, it is important that children and primary caregivers are involved in selecting a distraction strategy that is interesting to the child.

Sensory methods include rubbing the painful area, repositioning, massage, heat and cold therapy (Twycross & Stinson, 2013). Environmental approaches are concerned with a child's intrinsic need for security. The presence and nurturing actions of a child's primary caregiver, as well as a familiar and safe environment (i.e. having familiar personal objects, privacy and comfort) help children feel secure, which helps them cope with their pain (Sng et al., 2013; Woragidpoonpol et al., 2013).

The effectiveness of non-pharmacological interventions in the treatment of acute and chronic pain in children are well documented in systematic reviews (Davidson, Snow, Hayden, & Chorney, 2016; Lian, Pheng, & Yip, 2014; Wen et al., 2013; Woragidpoonpol et al., 2013). These include studies examining children's pain associated with injury, childhood illness, medical conditions (Matsuda, 2017), clinical procedures such as intravenous catheterisation (Sadeghi, Mohammadi, Shamshiri, Bagherzadeh, & Hossinkhani, 2013) immunisations (Bikmoradi et al., 2017; Desprée & Langeland, 2016), and surgery (Wen et al., 2013; Woragidpoonpol et al., 2013). Advantages of non-pharmacological measures include: their cost effectiveness, the potential to avoid adverse effects of medications, and they are generally feasible, accessible and easily initiated by healthcare professionals, caregivers and the child (Bikmoradi et al., 2017; Woragidpoonpol et al., 2013).

## **2.4 Factors that Influence Pain Management**

As highlighted in the earlier discussion related to pain assessment models, factors that influence the management of children's pain are complex and can be broadly categorised as aspects related to the child, the healthcare professional and the organisation (Twycross, 2013a). It is understood that a child's expression of pain is the precursor to the healthcare professional's assessment of pain (Voepel-Lewis et al., 2012). As outlined previously, the way children express their pain is influenced by a number of factors. It is well established that sociocultural factors (e.g. language, cultural beliefs, values and norms) influence the way children express their pain (Finley et al., 2009; Nortje & Albertyn, 2015; Twycross et al., 2015). Children may also mask their pain to avoid perceived consequences of pain like not being able to participate in usual daily activities or embarrassment in front of their peers (Sng et al., 2013). The physical and social environment may also contribute to a child's reluctance to report pain such as being in hospital with unfamiliar people around (healthcare

professionals, other patients) or the absence of a child's primary caregiver (Craig, 2015; Franck & Bruce, 2009). A child's pain memories from previous experiences may also influence their pain expressions and behaviours (Noel et al., 2017). If a healthcare professional does not have adequate knowledge or skills to recognise these aspects that may influence a child's report of pain, assessment may be inadequate (Craig, 2015; Schiavenato & Craig, 2010).

Knowledge deficits by healthcare professionals related to the physiology of pain, pain assessment tools and/or pharmacological and non-pharmacological interventions have also been identified as major barriers to optimal pain management for children (Czarnecki et al., 2011; Herd et al., 2009; Namnabati, Abazari, & Talakoub, 2012; Twycross & Collis, 2013). In addition, a lack of knowledge about childhood development that influences the way children behave and express their pain, have been linked to children's pain being unrecognised and undertreated by healthcare professionals (Twycross, 2013b). A lack of empathy, as well as personal beliefs and biases about pain may further contribute to the way a healthcare professional manages pain (Craig, 2015; Schiavenato & Craig, 2010; Twycross, 2013b).

Organisational barriers to effective pain management for children have also been identified. A heavy workload for staff, competing priorities, a perceived lack of time (Czarnecki et al., 2011), and low morale among staff (Twycross, 2013b) have been associated with inadequate management of children's pain. In the context of the ED, factors such as urgency of medical treatment; the fast paced, dynamic environment and overcrowding also contribute to the difficulty of adequate pain management for children (Ortiz et al., 2012; Scott et al., 2013).

Despite a plethora of research examining children's pain and the development of evidence-based recommendations for effective pain management, children continue to unnecessarily experience pain while in hospital (Davidson et al., 2016; Stevens et al., 2012; Twycross & Collis, 2013; World Health Organisation, 2012). Evidence has emphasised the importance of seeking children's perceptions of pain and pain management to better understand their needs and expectations when they have pain (Kortesluoma, Nikkonen, & Serlo, 2008; Twycross & Finley, 2013; Wen et al., 2013) in order to improve pain management for children.



## 2.5 Children's Voices: Research with Children

Research exploring children's perspectives of pain are scarce compared with those exploring adult pain experiences (Esteve & Marquina-Aponte, 2012). To date, many studies examining children's pain have adopted quantitative methods, or sought the perspectives of adults who have intimate knowledge of the child (i.e. primary caregivers or healthcare professionals) (Griffin, Polit, & Byrne, 2008; He et al., 2011; Simons, Carter, Bray, & Arnott, 2015; Smith, Reinman, Schatz, & Roberts, 2017). While results of these studies are important to our understanding and management of children's pain, capturing the entire experience of pain from the child's perspective is not possible using exclusively quantitative methods or seeking adult perspectives on matters that involve children.

There has been increasing understanding of the importance in seeking children's experiences and perspectives as separate to adults. This has resulted in a shift towards qualitative approaches conducted *with* children (Carter & Ford, 2013). These approaches enable children to have a voice on issues that involve them, a notion which aligns with principles advocated by United Nations in the Convention of the Rights of a Child (United Nations, 1989).

Child centred approaches to data collection place emphasis on empowering children to share their perspectives in a way that respects their capacities, interests, skills and experiences (Carter & Ford, 2013). Factors such as developmental and cognitive capabilities of children as well as practical considerations and building rapport and trust can make involving children in research more complex than adult participants (Carter & Ford, 2013; Twycross, 2012). It is also important to consider the influence of the research setting and people present during the interview (ie. primary caregivers, siblings) (Huang, O'Connor, Ke, & Lee, 2016). Adopting an approach to data collection that engages children and resonates with their daily activities also needs particular consideration (Carter & Ford, 2013; Twycross, 2012).

Arts based approaches, such as children undertaking activities like drawing, play and storytelling have emerged as child orientated and child directed approaches to data collection that offer close and direct engagement with children while inviting a deeper understanding of their perspectives (Driessnack, 2005; Carter & Ford, 2013). These approaches are often used alongside traditional data collection techniques such as

interviews and focus groups to help expand the means of expression available to the child and to facilitate the child's communication and interpretation of their experiences (Carter & Ford, 2013).

The draw, write and tell (DWT) (Angell, Alexander, & Hunt, 2015) is an example of an arts based participatory approach to data collection that is child centred and child directed. This technique involves asking children to draw a picture, and write words in response to interview questions, while responding verbally. The marriage of the arts based approach and dialogue inherent to the DWT process offered a fitting approach to gather data while exploring children's pain experiences because it allows children to express aspects of their pain which may have been difficult to articulate using language alone. The various issues faced when using the DWT with children are similar to other arts based approaches, some of which include; the influence of materials used (paper size, pencils/paint colours, props) (Carter & Ford, 2013; Angell et al., 2015) and the presence of primary caregivers on data quality (Priddis & Howieson, 2012); establishing rapport and trust with the child; and ensuring that the approach to data analysis preserves the child's perspective (Driessnack, 2005; Carter & Ford, 2013). The DWT technique, including its challenges and benefits when used with children in research are discussed in detail in Chapter 4 and Chapter 5.

## **Chapter 3 The Experiences of Acute Pain of Children Who Present to a Healthcare Facility for Treatment: A Systematic Review**

This chapter provides a copy of the manuscript that was accepted for publication in the Joanna Briggs Institute (JBI) Database of Systematic Reviews and Implementation Reports. This manuscript is a systematic review (SR) aggregating findings of children's experiences of pain in healthcare settings. The process adhered to that of the JBI for qualitative studies, therefore a protocol was blind peer reviewed (and published) prior to undertaking the SR. Copyright permission was obtained from the Journal (Appendix N) and tables and figures which were appended to the published manuscript are provided in the appendices section of this thesis (Appendix A-G). This SR was undertaken to critically analyse qualitative studies examining children's pain experiences and to synthesise the findings from those that satisfied the evaluation criteria. During literature searches for this SR, it was noted that studies examining children's experiences of pain within the ED were limited. For this reason, the literature search was widened to include studies exploring children's experiences of acute pain while receiving treatment in a healthcare facility

The aim of the SR was to identify, evaluate and synthesise the existing qualitative evidence on children's (aged four to 18 years) experiences of acute pain and pain management, within a healthcare facility. This included identifying children's expectations of other people (eg. primary caregivers, nurses, healthcare professionals) in managing their acute pain.

### **Reference:**

Pope, N., Tallon, M., McConigley, R., Leslie, G., & Wilson, S. (2017). The experiences of acute pain of children who present to a healthcare facility for treatment: A systematic review of qualitative evidence. *JBI Database of Systematic Reviews & Implementation Reports*, 6 (15), 1612–1644. DOI: 10.11124/JBISRIR-2016-003029.

## **3.1 Executive Summary**

### **Background**

Pain is a universal and complex phenomenon that is personal, subjective and specific. Despite growing knowledge in paediatric pain, management of children's pain remains suboptimal and is linked to negative behavioural and physiological consequences later in life. As there was no synthesis of these studies, it was timely to undertake a systematic review.

### **Objectives**

To identify, evaluate and synthesize the existing qualitative evidence on children's experiences of acute pain, including pain management, within a healthcare facility.

### **Inclusion criteria**

#### *Types of participants*

Children aged four to 18 years (inclusive) attending a healthcare facility who experienced acute pain associated with any injury, medical condition or treatment.

#### *Phenomena of interest*

Children's experiences and perceptions of their acute pain, pain management and expectations of others in managing their pain. Studies on children's experiences of pain in the postoperative context were excluded as a systematic review exploring this phenomenon had previously been published. Studies reporting on children's experiences of chronic pain were also excluded.

#### *Context*

Any healthcare facility including general practitioners' surgeries, hospitals, emergency departments and outpatient clinics.

#### *Types of studies*

Qualitative studies including phenomenology, grounded theory, ethnography, action research and feminist research designs.

## **Search strategy**

Using a three-step search strategy, databases were searched in December 2015 to identify both published and unpublished articles from 2000 to 2015. Studies published in languages other than English were excluded.

## **Methodological quality**

All studies that met the inclusion criteria were assessed by at least two independent reviewers for methodological quality using a standardized critical appraisal tool from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI).

## **Data extraction**

Data were extracted from the papers included in the review using standardized data extraction tool from JBI-QARI.

## **Data synthesis**

Findings were pooled using JBI-QARI. Findings were rated according to their level of credibility and categorized based on similarity in meaning and then were subjected to a meta-synthesis.

## **Results**

Four studies were included in this review. Two meta-syntheses were generated from five categories based on 21 findings: first, children can express their pain experiences in terms of cause, location, meaning and quality. Children's pain experiences include both physical and psychological dimensions. Children's pain experiences are influenced by their previous pain experiences, pain expectations and sociocultural factors. Second, children use a range of cognitive/behavioural and sensory/physical self-soothing strategies not only to help manage their pain, but also rely on the actions and presence of others as helpers when they are in pain.

## **Conclusion**

Children's pain is a multi-dimensional complex phenomenon relying upon a multi-modal approach to management. Children as young as four years are capable of articulating their pain in terms of location, intensity and depth. The way children perceive, express and respond to pain is shaped by sociocultural factors, previous pain experiences and their expectations of pain. Children, parents and healthcare professionals play an important role in managing children's pain experiences.

## Keywords

Acute pain; children; experience; pain management; perceptions

**Table 3.1 Summary of Findings**

ConQual (Munn, Porritt, Lockwood, Aromataris, & Pearson, 2014)

Synthesised finding	Type of research	Dependability	Credibility	ConQual Score
Children can express their pain experiences in terms of cause, location, meaning and quality. Children's pain experience includes both physical and psychological dimensions. Children's pain experiences are influenced by their previous pain experiences, pain expectations and sociocultural background	Qualitative	Downgraded 1 Level †	Downgraded 1 Level ‡	Low
Children are able to identify a range of cognitive/behavioural and sensory/physical self-soothing strategies to help manage their acute pain. Children also relied on the actions and presence of others as helpers when they are in pain	Qualitative	High	Downgraded 1 Level ‡	Moderate

†Downgraded one level due to common dependability issues across the included primary studies (the majority of studies had no statement locating the researcher and no acknowledgement of the influence on the research).

‡Downgraded one level due to a mix of unequivocal and equivocal findings.

*Systematic review title:* The experiences of acute pain of children who present to a healthcare facility for treatment: a systematic review of qualitative evidence

*Population:* Children aged four to 18 years (inclusive) attending a healthcare facility who had experienced acute pain

*Phenomena of interest:* Children's experiences of acute pain, their perceptions relating to pain management, and their expectations of other people in managing their pain

*Context:* Any healthcare facility or service, including, but not limited to, general practitioners' surgeries, hospitals, emergency departments and outpatient clinics

## 3.2 Background

The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (Ortiz et al., 2012, p. 2701). The pain experience is multifaceted and complex, extending beyond the physiological interpretation of a noxious stimulus, encompassing other dimensions, including; psychological, cognitive, sociocultural, affective and emotional factors (Atherton, 1995; Gyländ, 2012; Ortiz et al., 2012). Pain can be described as chronic (persisting for three months or more) or acute (a time limited response to a noxious stimuli) (Pain Australia, 2011). Over the past 50 years clinical research has made revolutionary contributions to better understanding paediatric pain. The once pervasive and erroneous notion that infants do not physiologically experience pain the same way as adults has been firmly dispelled. We now know that nervous system structures associated with interpretation of pain are functional as early as fetal development (Akuma & Jordan, 2012; Drendel et al., 2011). Despite this critical knowledge and the growing global commitment to improving paediatric pain management in clinical practice, evidence repeatedly suggests that pain management remains suboptimal and inconsistent, a phenomenon commonly referred to as oligoanalgesia (Bailey et al., 2012; Crocker et al., 2012; Drendel et al., 2006; Scott et al., 2013). Research evidence has linked poorly managed pain in the paediatric population to negative behavioural and physiological consequences later in life (Akuma & Jordan, 2012; Babl et al., 2012; Drendel et al., 2011). Effective pain management is therefore a priority area for healthcare professionals. Improved understanding of children’s experiences of acute pain may lead to improved pain management and a reduction in oligoanalgesia.

In the 1970s and 1980s, studies began exploring the subjective experiences of paediatric pain and discovered children’s abilities to articulate their pain experiences (Gaffney & Dunne, 1986; Hurley & Whelan, 1988; Ross & Ross, 1984; Scott, 1978; Unruh, McGrath, Cunningham, & Humphreys, 1983). Further, children were able to link causes and consequences of their pain (Gaffney & Dunne, 1986; Hurley & Whelan, 1988; Unruh et al., 1983). Developmental trends or age-related patterns with regards to children’s expressions and experiences of pain were identified (Gaffney & Dunne, 1986). Recent studies have also recognized apparent trends in children’s understanding and expressions of pain; these follow an age and cognitive development

trajectory in line with Piaget's theories of development (Atherton, 1995; Drendel et al., 2011; Esteve & Marquina-Aponte, 2012).

For many children psychosocial aspects of pain, including emotions like fear, stress and anxiety, are often more unpleasant than the painful experience itself (Atherton, 1995; Babl et al., 2012; Ortiz et al., 2012; Sutters et al., 2007). Emotional responses such as distress and anxiety are commonly associated with the anticipation of pain, can exacerbate and intensify the pain experience (LeMay et al., 2010), and can significantly lower a child's pain threshold (Babl et al., 2012). One study that explored children's pain experiences using an observational pain assessment tool found that children who underwent "non-painful" procedures (such as restraint) had equal, and in some cases higher, pain scores than those who underwent painful procedures (such as intravenous cannulation) (Babl et al., 2012).

Several studies exploring paediatric pain within healthcare settings (including, but not limited to, general practitioners' surgeries, hospitals, emergency departments and outpatient clinics) have adopted quantitative methods (Babl et al., 2012; Herd et al., 2009; Scott et al., 2013). These studies included parents (Pölkki, Pietilä, Vehviläinen-Julkunen, Laukkala, & Ryhänen, 2002; Simons, Franck, & Roberson, 2001), and nurses' perspectives (Griffin et al., 2008; Van Hulle Vincent, 2007) of children's acute pain. While results of such studies have added to the existing body of knowledge that supports the need to focus on improving paediatric pain management, it has been suggested that failing to ask children directly risks not capturing experiences of pain from the children's perspectives in their entirety (Sutters et al., 2007; Twycross & Finley, 2013). Seeking the children's perspectives could provide a more reliable and adequate means of gaining insight into their needs and expectations when they are in pain.

A single centred study in Singapore used semi-structured face-to-face interviews (n=15) to explore children's experiences of pain management post-operatively. While the children, aged between six and 12 years, identified the role of analgesia in managing their pain, they also placed significant emphasis on the role of parents and healthcare professionals in implementing non-pharmacological interventions in pain management (Sng et al., 2013). These results are relevant as they provide insights into how children experience and express pain, and their expectations of healthcare professionals in managing their pain. These findings draw attention to effective pain



management approaches when caring for children. Similarly, a UK study adopted a descriptive, mixed methods design including the draw and write technique aimed at investigating children's views on what helped when they were in pain. The children (n=71) were between four and 16 years of age. Findings revealed that children viewed themselves as active agents in pain management while also placing significant emphasis on the importance of parents and nurses in managing their pain (Franck et al., 2008). In both studies, children valued nurses for social interactions, such as kindness and humour, rather than the provision of clinical care, including analgesia administration. Systematic reviews of quantitative studies have also shown that adjunct therapies such as distraction, visualization, relaxation and music are effective in managing the pain experience in children (Lian et al., 2014; Mu, Chen., & Cheng, 2009; Woragidpoonpol et al., 2013). Not only do these findings demonstrate the complexity of the pain experience for the child, they also support the notion that improved pain management may come from research that is designed to better understand the entire pain experience from the child's perspective.

Qualitative research delivers a holistic perspective and provides invaluable evidence in understanding how individuals perceive and manage their health. The knowledge gained through qualitative research offers unique insights into human experiences. These perspectives are important for health professionals who focus on caring and interaction (Holloway & Wheeler, 2010). This is particularly necessary to better inform health professionals and to help them understand the experiences of children with acute pain.

Meta-synthesis seeks to understand phenomena by aggregating and categorizing reported findings of individual qualitative studies that were seeking to explore the same phenomenon. Findings are categorized based on similarity in meaning, then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings. These synthesized findings can be used as a basis for evidence-based practice (Costi, Lockwood, Munn, & Jordan, 2014).

A search of the Joanna Briggs Database of Systematic Reviews and Implementation Reports, the Cochrane Database of Systematic Reviews, Medline and CINAHL, identified systematic reviews that examined interventions for managing children's pain (Chieng, He, & Chan, 2012; Lian et al., 2014; Woragidpoonpol et al., 2013), and

one that explored children's experiences specifically in the post-operative context (Wen et al., 2013), however to date, there has not been a formal systematic review published on the qualitative evidence of children's experiences of acute pain who were attending a healthcare facility.

The current qualitative systematic review aims to identify and synthesize results of studies that explored children's experiences of acute pain and pain management. The objectives, inclusion criteria and methods of analysis for this review were specified in advance in an a priori published protocol (Pope, Tallon, McConigley, & Wilson, 2015). However, a minor deviation from the protocol was necessary. The original protocol sought to consider studies that explored children's experiences of 'acute, non-surgical pain', which aimed to exclude studies that examined children's pain experiences in the post-operative context, as a systematic review that addressed post-operative pain specifically had already been published (Sng et al., 2013). Although the search strategy excluded post-operative pain, studies were identified that included subsets of children who had undergone surgery (Crandall, Miaskowski, Kools, & Savedra, 2002; Kortessluoma & Nikkonen, 2006; Kortessluoma et al., 2008). The children's pain experiences and perceptions of pain and pain management were not related specifically to the post-operative context, however data could not be disaggregated from the population of interest. Further, these studies had not been included in the systematic review that synthesized the evidence of children's post-operative pain experiences (Wen et al., 2013). Since the objective of the present review was about children's experiences of acute pain, these studies were considered for inclusion in the systematic review.

### **3.3 Objectives**

The aim of the systematic review was to identify, evaluate and synthesize the existing qualitative evidence on children's (aged four to 18 years) experiences of acute pain, including pain management, within a healthcare facility.

The specific objectives were to identify:

- Children's experiences of their acute pain, including pain management
- Children's expectations of others in managing their acute pain including, but not limited to parents and nurses

### **3.4 Inclusion Criteria**

#### **Types of participants**

The current review considered studies that included children aged four to 18 years (inclusive) who had attended a healthcare facility and experienced acute pain (of less than three months duration), caused by any injury, a medical condition or associated with medical treatment. Studies focusing on children who were younger than four years of age were excluded as these children typically have not developed linguistic skills that enable them to articulate their experiences (Franck et al., 2010; Stanford et al., 2005).

#### **Phenomena of interest**

The current review considered studies that explored children's experiences of acute pain, including pain management and their expectations of other people in managing their pain, including, but not limited to, parents and nurses. Studies that focused specifically on children's experiences of pain in the postoperative context were excluded as a systematic review exploring this phenomenon had previously been published (Wen et al., 2013). Studies reporting on children's experiences of chronic pain were also excluded.

#### **Context**

Any healthcare facility or service, including, but not limited to, general practitioners' surgeries, hospitals, emergency departments and outpatient clinics were considered.

#### **Types of studies**

The current review considered studies that focused on qualitative data, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

### **3.5 Search Strategy**

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using

all identified keywords and index terms was undertaken across all included databases. Third, the reference lists of all identified reports and articles were searched for additional studies. Studies published in English and studies published from 2000 to 2015 were considered for inclusion in this review. Family Centred Care, incorporates models of care where healthcare professionals no longer assume an expert role and work in partnership with families (Davis, Day, & Bidmead, 2002). This was introduced into paediatric healthcare in the late 1990's (Davis et al., 2002). This shift from a more expert hierarchical model to a partnership model is well supported in preceding literature (Fowler, Barnett, & McMahon, 2006; McKlindon & Barnsteiner, 1999). The change in the philosophy of care to children propagated an upsurge in research exploring children's perceptions of aspects of their health care. These studies recognized the value and importance in capturing children's perspectives (Wen et al., 2013). Previous to the year 2000, research examining children's perspectives was limited.

**The databases searched included:**

CINAHL, MEDLINE, Scopus, Science Direct, PsycINFO, Embase, Web of Science and the ProQuest Central platform.

**The search for unpublished studies included:**

Google Scholar, Mednar, ProQuest Dissertations and Theses

**Initial keywords used were:**

Children/child, paediatric/paediatric, experience, perception, pain, acute.

The full search strategy is provided in Appendix A.

### **3.6 Method of the Review**

Articles identified with the search strategy were first assessed by reading the title and abstract. Full text articles were obtained for the studies deemed relevant in order to assess whether they met the inclusion criteria. Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI)

(Appendix B). No disagreements arose between the reviewers, therefore the involvement of a third reviewer was not required.

The JBI-QARI appraisal instrument (Appendix B) comprises of 10 questions which address congruency between the philosophical basis of the study, study methodology and methods, how the data is represented and the interpretation of the results. The influences or biases of the researcher, and the relationship between the participants' extracts and conclusions drawn by the researcher were also critically examined. The JBI-QARI appraisal tool requires reviewers to allocate findings of 'yes', 'no', 'unclear' or 'not applicable'. In this review it was agreed that papers would be included if six of the ten appraisal questions were answered 'yes' and there was agreement between the reviewers. This was in keeping with previous systematic reviews of qualitative evidence (Costi et al., 2014; Wen et al., 2013), and ensured the nature and appropriateness of the methodological approaches were established to ensure representation of the voices and meanings of study participants.

### **3.7 Data Extraction**

Qualitative data were extracted from papers included in the review by two reviewers independently using the standardized data extraction tool from JBI-QARI (Appendix C). The data extracted included specific details about the study methods, the study setting, the phenomena of interest and findings of significance to the review aim and specific objectives. Where there was disagreement on the findings extracted, a third reviewer was required, and findings were discussed until agreement was reached.

Findings, as reported by the individual study's author, were extracted along with supporting illustrations (participant's quotes). Each finding was assigned a level of credibility according to the JBI QARI, these were: Unequivocal (evidence beyond reasonable doubt), credible (albeit an interpretation, plausible in the light of the data and theoretical framework), and unsupported (findings are not supported by the data, or lacking data).

### **3.8 Data Synthesis**

Qualitative research findings were pooled using JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represent that

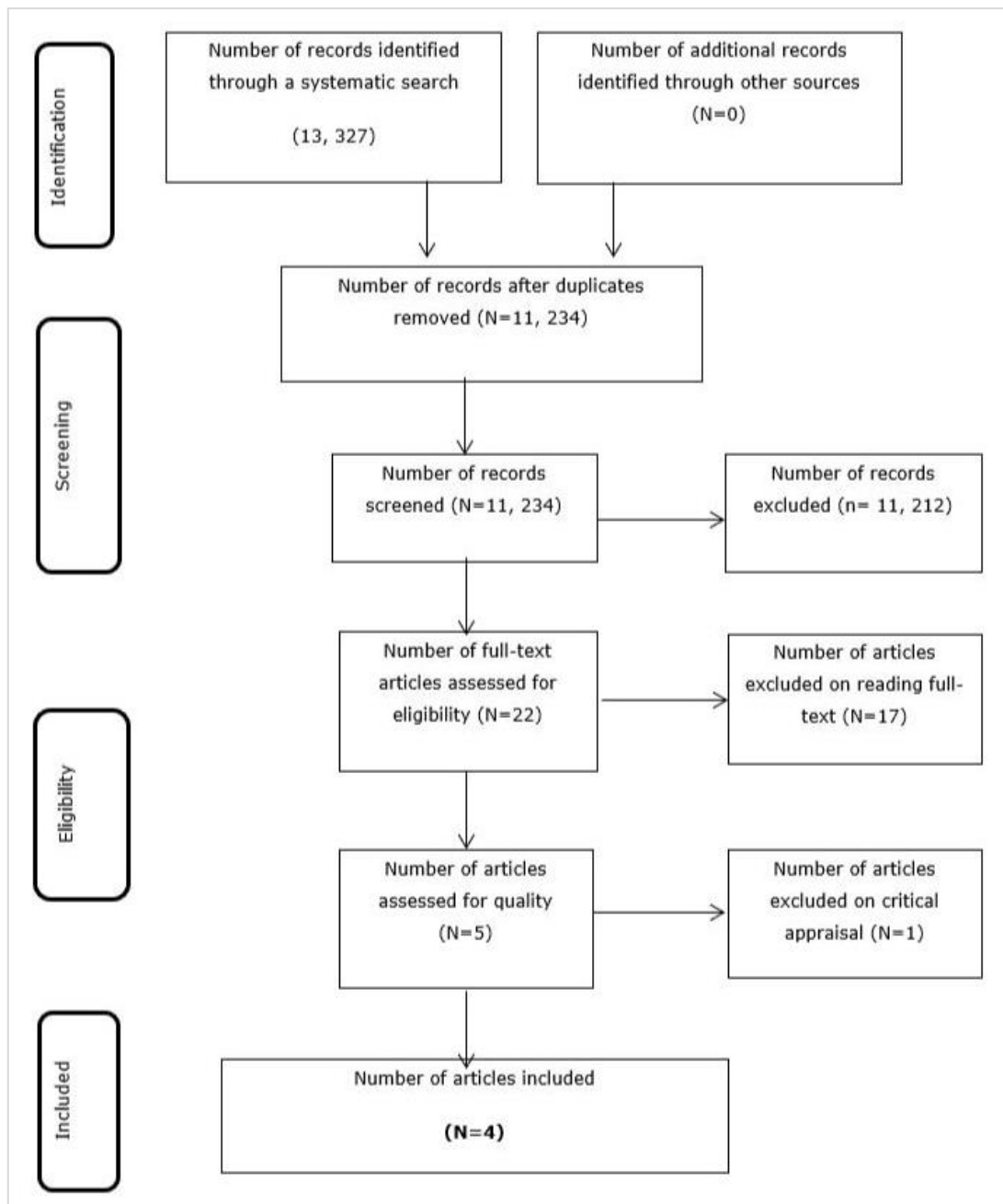
aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a comprehensive set of synthesized findings that could be used as a basis for evidence-based practice.

Three members of the review team examined each extracted finding and grouped them into draft categories collaboratively. The draft categories and their associated findings were then re-examined, discussed and refined two weeks later. The grouping of findings into categories was based on relatedness in terms of meaning. The synthesized findings were drafted by the primary author then discussed with a second reviewer for validation.

### **3.9 Results**

#### **Search results**

The initial literature search was conducted in December 2015, (last search date 30th December), and produced 13,327 records using pre-designed search strategies specific to each database. Following removal of duplicates a total of 11,234 articles with potential relevance remained. Where both a thesis and published paper were identified of the same work, the published paper only was included, and the thesis was excluded as a duplicate. The titles and abstracts were screened for relevance in relation to fulfilling the objectives of this systematic review and 11,212 articles were excluded, leaving 22 studies identified for full text retrieval and detailed assessment against the eligibility criteria. After reading the full text, 17 studies were eliminated based on not fulfilling the inclusion criteria (Appendix D) leaving five studies (Cheng, Foster, Hester, & Huang, 2003b; Crandall et al., 2002; Kortessluoma & Nikkonen, 2006; Kortessluoma et al., 2008; Nilsson, Hallqvist, Sidenvall, & Enskar, 2011a), for assessment of methodological quality against the JBI Critical Appraisal Instrument Checklist (Appendix B). The references of these five articles were hand-searched for papers previously not identified and no extra papers were selected for critical appraisal. The search process for review is depicted in Figure 3.1.



**Figure 3.1 Search process for review**

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic

Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097.

doi:10.1371/journal.pmed1000097

### ***Methodological quality***

Following methodological assessment by two reviewers, one of the five articles identified in Table 3.1 (Kortessluoma & Nikkonen, 2006) did not meet the criteria in the JBI QARI Appraisal Checklist for Interpretive and Critical Research, as it only fulfilled four of the ten criteria. (Refer to Table 3.2). The article was excluded and the reasons for exclusion are detailed in Appendix D.

**Table 3.2 Assessment of methodological quality of excluded study**

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Kortesluoma, R & Nikkonen, M 2006	Y	Y	Y	U	U	N	N	Y	U	N

Note: Y=Yes, N=No, U=Unclear

The four remaining studies (Cheng et al., 2003b; Crandall et al., 2002; Kortesluoma et al., 2008; Nilsson et al., 2011b) all met five of the criteria: congruency between methodology and research question or objectives (criterion 2), methodology and methods (criterion 3), methodology and data analysis (criterion 4), participants and their voices adequately represented (criterion 8), and conclusions flow from analysis or interpretation of results (criterion 10). All the studies were assessed as ethical, but one did not report receiving ethics approval from an appropriate body (Cheng et al., 2003b). An attempt was made to contact the authors to ascertain information on the research ethics approval body but was unsuccessful.

The weakest areas were criteria 6 (researcher located culturally or theoretically) and 7 (influence of researcher on the research, or vice-versa). Two studies did not meet criterion 6 (Crandall et al., 2002; Kortesluoma et al., 2008), and two did not meet criterion 7 (Crandall et al., 2002; Nilsson et al., 2011b), No study met all criteria. (Refer to Table 3.2 and Table 3.3).

**Table 3.3 Assessment of methodological quality of included studies**

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Nilsson, S, Hallqvist, C Sidenvall, B & Enska, K, 2011	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Cheng, S, Foster, R, Hester, N, Huang, C, 2003	Y	Y	Y	Y	U	Y	Y	Y	U	Y
Crandall, M, Miakowski, Kools, S, Savedra, M, 2002	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Kortesluoma, R & Nikkonen, M, Serlo, W, 2008	N	Y	Y	Y	Y	N	Y	Y	Y	Y
<b>%</b>	<b>75</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>75</b>	<b>50</b>	<b>50</b>	<b>100</b>	<b>75</b>	<b>100</b>

Note: Y=Yes, N=No, U=Unclear



### *Description of included studies*

The four included studies (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b), were papers published over a nine-year period (2002-2011). One study specified the qualitative methodology and underlining philosophy being employed as grounded theory (Crandall et al., 2002), the remaining three studies used qualitative designs which were titled as “qualitative descriptive” (Cheng et al., 2003b; Kortessluoma et al., 2008; Nilsson et al., 2011b). All studies employed semi-structured interviews for data collection. One study also used two self-reporting pain assessment tools to enhance data collection, and also reviewed medical records to ascertain further information (Crandall et al., 2002).

The four countries represented in the studies were Taiwan, (Cheng et al., 2003b) The United States of America (Crandall et al., 2002), Finland (Kortessluoma et al., 2008), and Sweden (Nilsson et al., 2011b). A variety of clinical contexts were represented including, surgical wards, medical wards, emergency departments, intensive care units and a paediatric day care unit. One study was conducted across five hospitals within one country (Cheng et al., 2003b), another was conducted across four wards within the one hospital (Kortessluoma et al., 2008), and the remaining two studies recruited participants from one clinical area within one hospital (Crandall et al., 2002; Nilsson et al., 2011b).

All studies (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b), focused on children’s (age range 4-17 years) perspectives only. Sample sizes varied from 13 to 90 participants, providing a total of 186 children, 54.3% males (n= 101) and 46.7% females (n=85). The languages spoken by the children included English, Mandarin, Taiwanese, Finnish and Swedish.

In respect to the phenomenon of interest for this systematic review, all addressed a number of aspects of the topic including the subjective pain experiences of children and their perspectives on what helped them when they were in pain, including their expectations of other people in managing their pain. A summary of the characteristics of included studies is provided in Appendix E.

## **Findings of the review**

A total of 21 findings were extracted from the four studies (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b), and can be seen with the assigned level of credibility as detailed by JBI-QARI in Table 3.4 and Table 3.5. The accompanying illustrations for each finding are provided in Appendix F. The 21 findings were collated to form five categories created on the basis of similarities of meaning, and from these, two synthesized findings (meta-synthesis) were produced.

### ***Meta-Synthesis 1***

Children can express their pain experiences in terms of cause, location, meaning and quality. Children's pain experience includes both physical and psychological dimensions. Children's pain experiences are influenced by their previous pain experiences, pain expectations and sociocultural background.

This meta-synthesis was created from two categories being "The physical and psychological dimensions of pain" and "Previous knowledge and experiences influence the pain experience", which emerged from 11 findings. Levels of credibility as detailed by JBI-QARI are also included for each finding.

Children expressed both the physical and psychological dimensions of their pain. Children were able to pinpoint their pain, and communicate they had pain using a variety of 'pain words'. Children also described the intensity, severity and quality of their painful sensations using sensory, affective and evaluative words. Pain expressions and descriptions tended to be in line with the child's cognitive development. Children's pain had an apparent psychological dimension, emotions such as fear and apprehension were commonly expressed by the children as a result of their pain experience. These emotional responses were not only associated with the physiological pain processes, but also the anticipation of pain and perceived pain consequences. A child's perception of and reaction to pain is also influenced by other factors such as, previous experiences, the child's expectations of pain, and their sociocultural background.

**Table 3.4 Results of meta-synthesis of qualitative research.  
Meta-synthesis 1**

<b>Finding</b>	<b>Category</b>	<b>Synthesized finding</b>
Injury characteristics [C]		
Present pain descriptions [U]		
Meaning of pain [U]	The physical and psychological dimensions of pain	Children can express their pain experiences in terms of cause, location, meaning and quality. Children’s pain experiences include both physical and psychological dimensions. Children’s pain experiences are influenced by their previous pain experiences, pain expectations and sociocultural factors
Quality of pain [U]		
Definition of pain [U]		
Causes of pain [C]		
Previous pain experiences [C]		
Pain expectation [U]	Previous knowledge and experiences influence the pain experience	Children’s pain experiences are influenced by their previous pain experiences, pain expectations and sociocultural factors
Pain acceptance [C]		
Pain descriptions recalled according to context [C]		
Unrelieved pain consequences [C]		

Note: U= Unequivocal, C=Credible

### ***Meta-Synthesis 2***

Children are able to identify a range of cognitive/behavioural and sensory/physical self-soothing strategies to help manage their acute pain. Children also relied on the actions and presence of others as helpers when they are in pain.

The meta-synthesis was created from three categories, being “Cognitive/behavioural and sensory/physical self-soothing actions children used to help manage their pain and anxiety”, “Feeling secure” and “Actions of others to help manage children’s pain”, which developed from 10 findings. Levels of credibility as detailed by JBI-QARI are also included for each finding.

Children used a variety of self-management skills to relieve their pain, which included cognitive/behavioural and sensory/physical strategies. Children need to feel secure as a form of comfort when they have pain. Feelings of security emerge when a child feels safe within their environment and when they are in the presence of family or people they trust. Developing trust with a child is an important consideration for healthcare professionals. Children identified the role of healthcare personnel, namely nurses, in helping them when they are in pain. Children valued nurses who were gentle, patient and clinically competent. Nurses who lacked these qualities were perceived by the children as unhelpful in managing their pain.

**Table 3.5 Results of meta-synthesis of qualitative research.  
Meta-synthesis 2**

<b>Finding</b>	<b>Category</b>	<b>Synthesized finding</b>
Children's self-help strategies for pain [U] Actions adolescents' recalled using to manage pain [U] Participation [U] Nothing can help [U]	Cognitive/behavioural and sensory/physical self-soothing actions children used to help manage their pain and anxiety	Children use a range of cognitive/behavioural and sensory/physical self-soothing strategies to help manage their pain, but also rely on the actions and presence of others as helpers when they are in pain
Security [C]	Feeling secure	
Significant others as helpers [C] Other generated sources of pain relief [U] Distraction [U] Expectations of professional help [U] Clinical competence [U]	Actions of others to help manage children's pain	

Note: U= Unequivocal, C=Credible

### **3.10 Discussion**

Despite the global commitment to improving paediatric pain management in clinical practice, evidence repeatedly suggests that pain management remains suboptimal and inconsistent (Bailey et al., 2012; Crocker et al., 2012; Drendel et al., 2006; Scott et al., 2013). This systematic review of qualitative evidence was undertaken to better understand children's (aged four to 18 years) experience of acute pain and their perceptions of pain management, including the role of other people such as family members and healthcare professionals. Findings from the present review highlight the multifaceted nature of children's pain, which is consistent with findings from a recent systematic review by Wen et al., (2013) who explored children's experiences of their post-operative pain. Children's previous pain experiences, pain expectation and sociocultural background play an integral part in the pain experience. Children as young as four are able to articulate their pain and identify strategies they considered effective in managing their pain. This is also in keeping with findings of previous systematic reviews exploring children's post-operative pain (Wen et al., 2013) and non-pharmacological pain management strategies (Woragidpoonpol et al., 2013), which advocate that children's expertise of their pain and as such self-reported pain is the most reliable method used in pain management. Children intuitively rely on several self-soothing strategies to help them when they have pain, yet also rely on the actions and presence of others, particularly their family and healthcare professionals, to help

them during their pain experience. A key finding of this review was that children also described characteristics of healthcare professionals that they considered unhelpful in managing their pain.

Although only four studies were included in this review, they were conducted in different countries around the world and a variety of clinical contexts were represented including, medical wards, emergency departments, intensive care units, surgical wards, and a paediatric day care unit. This global representation from various clinical contexts is useful as it supports generalizability of the findings. The weakest areas in the quality assessment of the studies related to establishing the location of the researcher and any influence that may have been exerted both culturally and theoretically within the studies. However, overall, the quality of the included studies is considered high, (JBI level of evidence II) therefore the findings of this review produced useful evidence on children's experiences of acute pain and pain management within a healthcare facility.

The first synthesized finding; 'Children can express their pain experiences in terms of cause, location, meaning and quality. Children's pain experiences include both physical and psychological dimensions. Children's pain experiences are influenced by their previous pain experiences, pain expectations and sociocultural factors', identified the children's perspectives on their acute pain experiences.

Children were able to express both the physical and psychological dimensions of their pain, including unpleasant physiological sensations and emotional responses experienced as a result of pain. These findings are consistent with prior definitions that explain pain as a complex sensory and emotional subjective phenomenon (Atherton, 1995; Ortiz et al., 2012) and support the need for a comprehensive, multimodal approach to effectively manage children's pain experiences.

Very young children were able to verbally communicate that they had pain using a variety of pain related vocabulary and phrases (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). This is in keeping with previous quantitative research studies that have identified that pain words emerge in children's' vocabulary from as young as 18 months old and develop as they build linguistic competence (Franck et al., 2010; Stanford et al., 2005). Findings from Wen et al.'s (2013) systematic review of children's post-operative pain experiences also identified

that young preschool children are capable of communicating their pain using a variety of pain words. An American study used a mixed methods approach to explore language most commonly used by children to describe pain, they found that the word 'pain' was used relatively infrequently by young children and gradually emerged in children's vocabularies (Stanford et al., 2005). This finding contrasted results from the study set in Taiwan included in the present review (Cheng et al., 2003b), where researchers found that 'pain' was a common word used by children as young as five years old to express they had pain. These findings draw awareness to the cultural differences that influence the way children use language to express their pain, and reminds healthcare professionals working with children to consider developmental and cultural factors that influence language used by children when assessing their pain.

Children used sensory, affective and evaluative words to describe the intensity, severity and quality of their pain. This is consistent with findings from the systematic review on children's pain in the post-operative context which showed that children were able to differentiate varying levels of the pain they experienced (Wen et al., 2013). The present review also revealed that children used metaphorical phrases to describe the quality of their pain and make their experience understandable. By relating pain to something known to them in their world, children are able to communicate the inexpressible dimension of their pain, making their pain experience more visible. Younger children's expressions and descriptions of their pain tended to be concrete, while older children's perspectives were more abstract and psychologically orientated. This pattern supports existing quantitative evidence that identified that children's understanding and description of pain was found to follow a characteristic sequence of increasing abstraction in line with their age and cognitive development (Drendel et al., 2011; Esteve & Marquina-Aponte, 2012; Franck et al., 2010; Gaffney & Dunne, 1986). This review has generated findings revealing that children across all ages also expressed experiencing various autonomic responses induced by their pain such as feeling 'dizzy' and 'sick' (Crandall et al., 2002), 'hot and cold' (Crandall et al., 2002), 'throwing up' and 'feeling shortness of breath' (Cheng et al., 2003b). These manifestations were a criterion of the children's pain intensity and draw awareness to the importance of adopting a holistic, multimodal approach to assess and manage children's pain, to capture and address the pain experience in its entirety.

Findings support the view that sociocultural factors also influence how children perceive, express, behave, and manage their pain. While vocalized crying is a widely acknowledged pain behaviour, the present review identified that some cultural norms discourage the overt expression of pain, where children are taught that vocal crying is inappropriate and distressing to others, as such muted pain behaviour is encouraged (Cheng et al., 2003b). These findings resonate with results from a study, by Jongudomkarn et.al., who explored perspectives of children living with pain in Thailand (Jongudomkarn, Aungsupakorn, & Camfield, 2006). Children were recruited from the community or were inpatients of a local hospital while undergoing treatment for a chronic illness. Findings illustrated the influence of Buddhism, where confrontation is avoided, and patience and endurance are promoted and Thai children are taught not to express their sorrow, pain or anger in case it displeases others. Culturally constrained behaviour may interfere with a child's behavioural expression of pain, and as such influence the way healthcare professionals assess and manage pain. This supports the need for a model of cross cultural care that emphasizes the value of healthcare professionals developing cultural competence and applying this to clinical practice (Finley et al., 2009).

The psychological dimensions of the pain phenomenon were also evident in the findings. Children expressed various emotional responses to pain including apprehension and distress, which were commonly associated with the anticipation of pain, and the physiological pain experience (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). These findings resonate with those of the review by Wen. et al., (2013), exploring children's post-operative pain, which found that children experienced negative emotions associated with their pain such as anxiety, sadness and anger. The present review has extended on these findings and showed that children also experience negative emotions relating to what they perceive as consequences of pain. Because of pain, children of all ages were worried about other things such as not seeing their family and friends (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008), dying (Crandall et al., 2002), and stigma (Cheng et al., 2003b; Crandall et al., 2002). Younger children were also concerned about how being in pain could impact their play, while older children expressed concerns relating to their academic performance (Cheng et al., 2003b) and loss of independence (Crandall et al., 2002). These findings reinforce and extend those of earlier work by

Woodgate and Kristjanson (1996) who employed a grounded theory design to explore hospitalized children's (age 2-7years) pain experiences. They found that children related being in pain to not being able to carry out their usual activities such as playing and running, and being free from pain meant that children were able to continue with things they enjoyed doing (Woodgate & Kristjanson, 1996). This finding was not reported in the review by Wen et al. (2013) of children in the post-operative context, which may reflect that the expectations of children who undergo surgery differ from those who experience acute pain as a result of unexpected injuries or acute medical conditions. Psychological reactions such as distress, negatively influence children's pain experiences and can exacerbate and intensify children's pain. These findings are in keeping with those of a systematic review by Chieng et al. (2012) who synthesized quantitative evidence to examine the correlation between peri-operative anxiety and pain in children. The authors showed that children who had higher levels of pre- and post-operative anxiety experienced a higher level of post-operative pain. Quantitative studies have also shown that these negative psychological responses to pain are often more unpleasant for the child than the painful experience itself (Babl et al., 2012; Drendel et al., 2011; Ortiz et al., 2012).

This review generated findings revealing that children's pain experiences are also influenced by previous experiences and expectations of pain. The children's pain expectation related to the quality and accuracy of information given to children about pain. Children who felt well informed and confident in mediating their needs expressed positive experiences (Kortesluoma et al., 2008; Nilsson et al., 2011b). By contrast children who felt they did not receive accurate information about the possibility of experiencing pain expressed feeling deceived and reported feeling unprepared (Cheng et al., 2003b). These findings parallel those of the systematic review by Wen et al. (2013) which showed that children expressed anxiety associated with their lack of information about their condition in the post-operative context. Children expect to be given honest and understandable information relating to their condition and the possibility of experiencing pain, and rely on healthcare professionals and their caregivers to provide them with such information.

Closely related to previous pain experiences and expectations of pain is pain acceptance, which is associated to the amount of pain a child was willing to experience. This review showed that some children viewed pain as a self-limiting process that they



needed to accept and endure (Crandall et al., 2002; Kortessluoma et al., 2008). Similarly, findings of a review undertaken by Cheng, Foster, and Hester (2003a) showed that pain acceptance was a predictor of children's pain experience, where children were able to identify a maximum level of pain they were willing to accept before requesting pain relief medication. Children's pain acceptance is a clinically relevant factor with implications for healthcare professionals caring for children with pain. These findings draw awareness to the role of healthcare professionals in collaborating with children and their families to better understand children's previous pain experiences, expectations and their pain acceptance. Individualized care should be orientated around the expressed needs of children and families, working in partnership and providing care with children rather than to children is essential to family centered care.

The second synthesized finding; 'Children use a range of cognitive/behavioural and sensory/physical self-soothing strategies to help manage their pain, but also rely on the actions and presence of others as helpers when they are in pain'. Children identified a number of factors they found helpful or not in managing their pain, including their expectations of health professionals and family.

Children intuitively used a variety of self-soothing skills to relieve their pain which included cognitive/behavioural and sensory/physical self-soothing strategies. These strategies helped to minimize and distract the children from unwanted thoughts and behaviours that resulted from their pain. The fact that these self-soothing strategies are intuitively driven, self-initiated and self-maintained by the children supports their effectiveness (Woragidpoonpol et al., 2013). This review uncovered little difference in the strategies used by children regardless of age. The positive effects of non-pharmacological pain relieving methods such as cognitive/behavioural and sensory/physical techniques have been widely documented in previous systematic reviews of qualitative and quantitative evidence exploring children's pain experiences and pain management strategies both in the post (Wen et al., 2013; Woragidpoonpol et al., 2013), and for children living with chronic pain (Mu et al., 2009). Recommendations from the Australian Pain Society also advocates the integration of non-pharmacological pain modalities, as important in alleviating the psychological dimensions of children's pain (Friedrichsdorf, 2014).

Children of all ages needed to feel secure as a form of comfort when they were in pain. Children are able to identify physical and relational aspects that helped them feel secure during their pain experience. Creating a safe environment involved children being in the presence of familiar people such as family members, friends, and healthcare professionals, namely nurses, with who they had developed trust (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). Having familiar objects and personal belongings with them also seemed to help the children's feelings of security (Kortessluoma et al., 2008). In their systematic review Wen et al. (2013) similarly found that a familiar and comfortable environment was important to children to relieve their post-operative pain. The present review revealed that in the absence of their family and friends, children's pain and distress were often exacerbated. One child expressed that just thinking about her family brought her comfort when she was alone and in pain (Crandall et al., 2002). These findings support the view that emotional states modulate human pain reactivity (Crandall et al., 2002).

Beyond being present, children also relied on the actions of others in helping them when they were in pain. Children looked to their family to advocate for them, provide information, emotional and physical comfort, and assist them with routine daily tasks (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). These actions created a feeling of safety and comfort that allowed the children to better deal with their pain. Similar findings were echoed in a systematic review by Hoon, Hong-Gu, and Mackey (2011) exploring parental involvement in their school-aged children's post-operative pain management. These authors also highlighted the role of healthcare professionals in promoting and supporting parental participation in helping their children when they were in pain. Like children, parents relied on receiving sufficient and understandable information relating to their child's pain, and expected to be involved in their children's care (Hoon et al., 2011).

The present review summarized the interventions and actions of healthcare professionals including nurses, doctors and emergency response staff (paramedics), that children identified as important in helping them when they were in pain. Nursing staff were the most commonly identified personnel in the provision of care to manage children's pain. Children expressed the benefits of receiving care from nurses who demonstrated professionalism and clinical competence (Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). Children also relied on nurses to

provide them with timely pain relief medication (Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). These findings were reiterated in the review by Wen et al. (2013) who found that children acknowledged nurses who helped their pain through clinical skills such as giving medications and dressing wounds. The role of the nurse in providing non-pharmacological strategies to help relieve children's pain was also clearly revealed. This finding was not illustrated in the review by Wen et al. (2013) who proposed that this was a reflection of nurses' inadequacies in their knowledge of non-pharmacological pain-relieving strategies. Conversely, findings from the present review supported the nurses' use of various non-pharmacological strategies, including taking time to spend with the child, demonstrating empathy, and actively listening to children (Cheng et al., 2003b; Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). These strategies were identified by the children as helpful when they had pain. The use of these strategies also supported the development of a trusting, therapeutic relationship between the children and their nurses, and fostered a sense of security in the unfamiliar environment. The benefits of nurses implementing these non-pharmacological pain relief strategies in the provision of care has been acknowledged in other systematic reviews exploring children's pain (Woragidpoonpol et al., 2013). When children develop trusting therapeutic relationships with nurses they report more positive experiences (Nilsson et al., 2011b). Conversely, an interesting key finding of this review is that children were able to identify and articulate characteristics of health care professionals that they perceived as unhelpful to them when they were in pain. Children were unable to build trust with staff who they perceived as dismissive, 'tough', lacking clinical skills or a gentle bedside manner (Crandall et al., 2002; Kortessluoma et al., 2008; Nilsson et al., 2011b). In these cases, children did not consider these staff as helpful when they were in pain. These findings were not reported in the review by Wen et al. (2013) and illustrate the importance of clinical competence and the value of holistic person centered care. This further supports the need for a genuine respectful and sensitive approach that is emphasized in partnership building which advocates children as active agents in their own pain management (Bidmead, Davis, & Day, 2002).

### **3.11 Limitations**

There are a number of potential limitations with this review. Due to resource limitations, studies published in languages other than English could not be included in this review. Further, three studies (Cheng et al., 2003b; Kortessluoma et al., 2008; Nilsson et al., 2011b) collected data via interviews in languages other than English, the data were translated into English for publication, this may have resulted in the loss of meaning intended by respondents and researchers.

While every effort was made to identify relevant studies and a systematic search was carried out, it is possible that some studies may have been missed. Qualitative studies indexing is poorer than for quantitative studies as they are often not referenced in the usually indexed search engines (Joanna Briggs Institute, 2014a).

This review pooled data from participants with acute pain within a healthcare setting. As such, studies that recruited children from outside of a healthcare setting were excluded. Also, studies examining children with chronic pain were excluded from this review. Whether children are hospitalized may not be a significant factor affecting their interpretation of pain.

### **3.12 Conclusion**

Results of this systematic review corroborate and reinforce the knowledge that pain in children is complex and encompasses physiological, psychological, behavioural, and developmental factors. Children as young as four years old are able to verbally express their pain experiences including the cause, location and quality of their pain. The way children perceive, express and respond to pain is shaped by sociocultural factors, previous pain experiences and their expectations of pain. Psychological dimensions of pain are important in children's pain experiences. Because of their pain, children expressed experiencing various negative emotions that were related to the physiological pain experience, as well as the anticipation of pain, and the perceived consequences of being in pain.

Healthcare professionals, families and the children themselves all play essential roles in the management of children's acute pain. Children of all ages intuitively drew upon various self-soothing strategies to help when they were in pain. The presence and

actions of family members and friends also helped children to feel secure in the unfamiliar hospital environment, which in turn provided comfort for their pain. Healthcare professionals, namely nurses, also contributed to the children's sense of security. Children felt safe and were able to develop trust in nurses who they perceived as competent, empathetic and who listened to them. A new finding that emerged in the present review was that children explicitly expressed that nurses who they perceived to demonstrate negative attributes, such as being 'tough', were unhelpful and a barrier to managing their pain. Improvements can be made in many areas of practice to ensure the multidimensional pain phenomenon is met with a multimodal pain approach. These are identified and discussed below. Joanna Briggs Institute Levels of Evidence have been assigned to each recommendation for practice. Details regarding JBI Levels of Evidence can be found in Appendix G.

### **Implications for practice**

The review revealed several recommendations for practice which can improve children's acute pain experiences within a healthcare setting.

1. Healthcare professionals need to bring to practice their knowledge and understanding of developmental factors which influence the way children express and manage their pain. Children's competence in expressing their pain needs to be appreciated and respected. Children should be encouraged and supported as active agents in their pain management. (Level II)
2. Healthcare professionals need to demonstrate clinical competence and professionalism when caring for children in pain. This includes providing children with accurate, honest and understandable information related to their condition. These actions embrace and facilitate partnerships with children and their families which fosters therapeutic trusting relationships. When children trust healthcare professionals they are more likely to feel secure and comfortable, which positively influences children's pain experiences. (Level II)
3. Knowledge of sociocultural factors that may influence children's pain experiences is required by healthcare professionals and applied to their practice. The way children express, perceive and manage pain is influenced by these sociocultural factors, which may impact the way healthcare professionals assess and manage children's pain. (Level II)

4. Ensuring that healthcare professionals' clinical, developmental and sociocultural knowledge and skills related to pain assessment and management are reflected in policy and practice guidelines. Attention should be drawn to the importance of incorporating non-pharmacological strategies as part of the comprehensive, multimodal approach to manage children's pain. Children find various self-soothing strategies such as cognitive/behavioural and sensory/physical methods effective in managing their pain. (Level II).
5. When assessing and managing children's pain, healthcare professionals need to bring greater consideration of factors beyond the physiological manifestations of pain that influence the pain experience for children. This includes acknowledging and managing the psychological and sociocultural dimension of the pain phenomenon. (Level II)
6. Healthcare professionals need to collaborate with children and their families to better understand children's previous pain experiences, expectations and their pain acceptance. Individualized care should be orientated around the expressed needs of children and families, working in partnership and providing care with children rather than to children is essential to family centered care. (Level II)

### **Implications for research**

To enhance our understanding of the pain experiences of children and to supplement knowledge gaps, research can be developed in the areas such as;

1. Exploring the effects of the biopsychosocial factors in home and community settings on children's expression and management of pain.
2. Exploring children's, parents and healthcare professionals' perspectives about what they feel are better ways of assessing and managing children's pain.
3. Exploring the qualities and characteristics of healthcare professionals that children and parents perceive as valuable or otherwise when caring for children in pain.
4. Developing and testing an innovative, evidenced based pain assessment tool using a systems theory approach to better capture children's entire pain experience

### **Conflict of interest**

No potential conflicts of interest noted.

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### *Chapter Summary*

This chapter provided the method and results of a SR on children's pain experiences while receiving treatment in a healthcare facility or service. Two meta-synthesised findings provided insight into children's pain experiences. Children's pain includes physiological and psychological dimensions influenced by several factors. Non-pharmacological strategies including cognitive/behavioural and sensory/physical measures help children when they have pain. While children are able to initiate these pain-relieving strategies, they also depend on primary caregivers and healthcare professionals to initiate these strategies for them. These findings offered insight into hospitalised children's pain and pain needs and informed the following study using the draw write and tell (DWT) detailed in Chapters Four and Five.

## **Chapter 4 Method**

To answer the research questions proposed in Chapter 1, a qualitative descriptive study design incorporating the DWT was selected. This chapter details the methods used in the study, including input from a stakeholder group, sampling approach, data collection and data analysis. The six steps of thematic analysis as described by Braun and Clarke (2006) are detailed and reflexivity is discussed. Finally, ethical considerations are presented. Throughout, aspects of trustworthiness are described.

### **4.1 Study Design**

A qualitative, descriptive design using an inductive approach was undertaken. Data were collected using the DWT technique (Angell et al., 2015). This participatory research technique offered a non-intimidating and engaging approach to examining children's perspectives, while accommodating their developmental age and stage.

### **4.2 Stakeholder Group**

Key stakeholders were engaged in the project to ensure the research question met the needs of children, families and staff in the ED. Members of the stakeholder committee included; a research fellow, two senior nurses and one nurse practitioner who worked in the ED, and a consumer representative; a mother of four children who had received care within the ED. The researcher arranged two meetings with members to clarify the aims and objectives of the study and to establish an efficient procedure for data collection that did not impact service provision to children and families attending the ED. A further meeting with stakeholders was undertaken ensuring they were engaged in the recruitment procedure, particularly across nursing staff shift changes, and to provide updates of the study's progress.

### **4.3 Setting, Sampling and Participants**

As outlined in Chapter 1 (page 18), the study was undertaken in the ED of a Western Australian public tertiary paediatric hospital. Convenience sampling offered a practical approach to recruitment in the initial stages. This provided the opportunity to target potential participants who shared knowledge or experience of the phenomenon of interest (Holloway & Wheeler, 2010). This non-probability approach entails



collecting data from people who are available and willing to participate in a study (Polit & Beck, 2014). To ensure a range of pain aetiologies were captured in the sample and maximise the scope of information uncovered, purposive sampling was also used.

Children aged between four to eight years old who presented to the ED in acute pain of any aetiology were included. Based on previous studies utilising similar data collection methods (ie. the draw and tell technique) (Franck et al., 2008; Twycross & Finley, 2013), children of this age range were likely to be able to participate in the interview and drawing activity. As the children needed to be able to communicate with the researcher, and because the medical needs of the children took precedence over the study, the following exclusion criteria were applied;

1. Children with an unstable medical condition classified on the Australasian Triage Score as Category 1 or 2 which included children requiring immediate medical treatment and those with severe pain.
2. Children or primary caregivers who did not speak English,
3. Children with a cognitive or neurological deficit,
4. Children with an altered conscious state.

Prior to commencing recruitment, three information sessions for staff who worked within PMH ED were facilitated by the researcher and a member of the stakeholder group. In these sessions the aims and significance of the study were explained, and any queries which arose were addressed. The recruitment of participants took place from May to September 2015. During this time the researcher was located at triage but not employed in the ED. On presentation at the ED, the triage nurse identified potential participants and advised the child and primary caregiver of the study. Children and primary caregiver(s) who were interested to know more about the study were then referred to the researcher who assessed whether the child met the inclusion criteria. Those who were eligible to participate were provided further information about the study and given a pack which included information sheets; one for the primary caregiver and one for the child, (See Appendix H and I) and the consent form (See Appendix J). The researcher explained the study to the child using the information sheet which was given to the child to review with their primary caregiver. The researcher was available for further questions that arose. In most cases, this engagement occurred while the child was awaiting medical review and/or treatment.

Primary caregivers who agreed to participate signed the consent form, and assent from the child was secured when able. Demographic details including the child's name, date of birth and gender were recorded on a data collection form (See Appendix K). Contact details for the primary caregiver were gathered, and a time and location for the interview were arranged. Clinical details related to the source of the child's pain, the child's pain scores on admission and discharge, and the medical treatment provided in the ED were collected from the child and hospital case notes following discharge from the ED. The researcher ensured recruitment and consent did not delay the child's clinical assessment and treatment in any way.

#### **4.4 Data Collection**

Interviews with children were conducted in a location convenient to the child and primary caregiver on or away from the hospital grounds. At the time of the interviews, all children were accompanied by their primary caregiver(s) who were the child's mother or father.

##### **Prolonged engagement**

Prior to beginning data collection, the researcher spoke with primary caregiver(s) about their role to help the child feel comfortable and secure, while remaining passive to the child's perspectives. Also, the researcher spent time engaging with the child in order to build rapport. During this time children shared stories on various topics such as school, friendships and also engaged in various play activities with the researcher such as playing with toys or reading books. This informal discourse helped to establish an atmosphere of trust. This form of prolonged engagement also helped to reduce any perceived imbalance of power between the child and the researcher, while establishing a supportive environment where the child was comfortable to share information (Horstman, Aldiss, Richardson, & Gibson, 2008). The interview proceeded when the child indicated they felt comfortable to do so, which indicated they trusted the interviewer.

##### **The interview**

To enhance recall of experiences, all face to face interviews with children took place between two and 48 hours of discharge from the ED. Children were offered twelve coloured pencils for the drawing activity and an A3 sized piece of paper to

accommodate their gross and fine motor skills. The top section of this paper was blank and intended for the drawing, the bottom had ruled lines for the children to write words and the reverse side of the page was blank. All participants were offered the same materials and encouraged to create their drawing on the page provided however they felt comfortable (ie. landscape, portrait or reverse side).

All interviews were audio recorded which began with an opening question such as ‘Could you please draw me a picture about how you felt when you were in pain?’ So that the children understood the question, the researcher adapted the language used to the context of each interview, so that the terms used were meaningful to each child. For example, words such as ‘hurt’ and ‘sore’ were used rather than ‘pain’ where appropriate. Children were also invited to write words about how they felt while they were in pain. This question was followed by queries and prompts by the researcher such as ‘tell me more about this part of your picture’, to encourage children to explain their drawings and any words they had written. In this way, the children’s drawings were a point of reference for the researcher to direct further questions. Children were able to take as long as they required to draw, write and tell their story. Semi-structured interview questions that guided data collection are presented in Table 4.1.

**Table 4.1 Guiding Questions for Interview**

Num	Interview Question
1	Draw a picture about how you felt when you were in pain*
2	Are there any words you would like to write about how you felt when you were in pain*? (I can help you with writing)
3	Tell me about the picture and the words you have written
4	What made the pain* feel better/go away*?
5	What did nurses do when you were hurting*?
6	What do you think nurses should do to help your pain* feel better*?

*Note.* Questions 1-3 adapted from “Children's and parents' perceptions of postoperative pain management: a mixed methods study,” by A. Twycross and G.A. Finley, 2013, *Journal of Clinical Nursing*, 22(21/22), p.3095  
 Questions 4- 6 adapted from “Postoperative pain management experiences among school-aged children: a qualitative study,” by Q. W. Sng et al. 2013, *Journal of Clinical Nursing*, 22(7-8), p.958. \*Term used was adapted so that they were meaningful to the child.

Guiding interview questions were based on previous studies which examined children’s post-operative pain experiences (Sng et al., 2013; Twycross & Finley, 2013)

and were modified to meet the research objectives, the context of this study and stakeholder feedback.

The audio recordings were transcribed verbatim by the researcher, which helped maximise immersion in the data. To enhance recall and accuracy, transcription was undertaken within two days of the interview taking place. Field notes were maintained by the researcher which included contextual information about the time, place and people present during the interview. Details related to non-verbal interactions observed by the researcher, and any relevant comments made by the child or their primary caregiver once the audio recorder was switched off were also recorded as field notes (Creswell, 2013). Descriptive field notes are essential to being thoroughly absorbed in the data and the study context, which help establish credibility (Creswell & Miller, 2000). Furthermore, these notes contributed to the data as non-verbal cues such as the child's positioning in relation to their primary caregiver, as well as their engagement in the drawing activity were recorded. These details captured in the field notes provide thick, rich descriptions to assist in transferability of findings (Lincoln & Guba, 1985). In addition to these field notes, reflexive notes were recorded by the researcher immediately following each interview. These notes allowed the researcher to be located in the study and consider any biases that may have influenced the interview process (Holloway & Wheeler, 2010). Given that the researcher was a mother to a young infant at the time, it was important to consider any potential influences related to collecting data from young children that was consistent across all age groups. (Lincoln & Guba, 1985)

Theoretical saturation was reached at approximately 13 interviews, at a point where no new data were obtained and gathering further data was unlikely to provide new insight (Morse, Lowery, & Steury, 2014). While data saturation means sampling to redundancy of information or themes (Lincoln and Guba, 1985), 'theoretical saturation' denotes that no new concepts are identified which are important to the study agenda (Holloway and Wheeler 2010). It is in this context that saturation was defined in this study. Data saturation was considered to be reached in relation to responses and not in relation to characteristics of the sample such as gender or age. A further two interviews were undertaken to confirm theoretical saturation.

## 4.5 Data Analysis

An inductive approach adhering to the six phases of thematic analysis as described by Braun and Clarke (2006) was employed to analyse the interview transcripts alongside reference to the field notes. Thematic analysis offered a rigorous and flexible approach to analysis during which the researcher sought to examine underlying beliefs and conceptualisation (Braun and Clarke 2006), to gain insight into participants' experiences. Thematic analysis was applied to the transcripts, not to the children's drawings. Each phase of the analysis was undertaken in collaboration with the supervisory team, and these phases are described below.

**Phase One:** Familiarisation with the data. To maximise data immersion, all audio recorded interviews were transcribed verbatim by the author. Transcripts were read and re-read by the author whilst simultaneously listening to the audio recordings. Each transcript was also re-read alongside reference to the field notes. The process offered a form of prolonged engagement with the data and supported credibility of findings (Lincoln & Guba, 1985). During phase one initial ideas and patterns were noted and discussed.

**Phase Two:** Identifying patterns and assigning codes. Similar features of the data were grouped together to form codes. The codes were named and organised using NVivo 10© software (QRS International, 2014). As a way to illustrate the codes, data extracts were linked to the codes. Some extracts were linked to more than one code. Alongside this, notes were made in relation to patterns emerging from the data. Further to this, reflexive notes were maintained by the researcher throughout all phases of data analysis. These notes offered an audit trail, contributed to confirmability and dependability, and helped to support trustworthiness of the findings (Lincoln & Guba, 1986).

**Phase Three:** Examining and grouping codes. Codes were examined and re-examined to identify any relationship between different codes. When commonalities between codes were noted, the codes were collated to form categories. The categories were supported with relevant data extracts which were reviewed and collated in the same way and linked to the categories. Incorporating data extracts in this way contributes to rigour of the analysis (Lincoln & Guba, 1986). As in phase two, credibility and dependability were supported by maintaining notes during this process. Mind-maps were also created as visual representation to assist in examining relationships between

the codes and categories, and between the categories themselves. This process helped to gain a sense of the emerging themes.

**Phase Four:** Reviewing and refining initial themes. To further support credibility, original codes and categories were further re-examined by the researcher and a member of the supervisory team independently. Collated data extracts for each category were reviewed and discussed to determine whether they formed a coherent pattern. Categories were refined, grouped and reviewed to form initial themes. This process was conceptualised in a thematic tree. The data extracts for each theme were then reviewed to determine whether they formed a coherent pattern. Based on this, themes were refined, and potential new themes were discussed.

**Phase Five:** Naming defined themes. Collated data extracts were examined and re-examined. Themes were further refined and the essence of what each theme was about was noted. During this refinement, subthemes were identified. Each theme, and subtheme were individually considered, as well as in relation to other themes and to the research objectives. Using an inductive approach throughout this process ensured the themes remained strongly connected to the data (Braun & Clarke, 2006). Themes were reviewed and discussed with the supervisory team.

**Phase Six:** Writing the report. Findings from the thematic analysis were reported and a conceptual framework was constructed to represent the named themes and subthemes, and their relationship to each other. The conceptual framework was used to guide the presentation and discussion of findings. Extracts were embedded in the findings to illustrate and support each finding. The results were discussed with the stakeholder group and in relation to the existing literature and to the research objectives.

## **Reflexivity**

In qualitative methods, the researcher is the data collection instrument therefore, cannot be separated from the research. To better hear and understand the perspectives of participants, and to allow an unbiased interpretation of the data, it is essential that the researcher can recognise their personal views, assumptions and experiences and consider how these may influence interpretation of data (Berger, 2015).

Throughout the process of recruitment, data collection and analysis the researcher, a mother of a newborn and a registered nurse with recent experience in paediatric

nursing, maintained reflexive notes as a way to locate herself in the research project and to openly and truthfully consider her thoughts and feelings (Holloway & Wheeler, 2010). Reflexivity also allowed the researcher to question any assumptions or preconceived ideas she had in relation to the research topic, and any expectations she had with regards to what the participants would disclose during the interviews (Luttrell, 2010). To further examine any influence the researcher may have had on the interpretation of data, these reflexive notes were discussed with the research team during the regular supervisory meetings. This process contributes to trustworthiness as it supports confirmability (Lincoln & Guba, 1986).

#### **4.6 Ethical Considerations**

Human Research Ethics Committee (HREC) approval was first granted from the Child and Adolescent Health Service (ref. 2014082EP). Following this, reciprocal ethics approval was granted from Curtin University's HREC (ref. HR46/2015). Copies of each committee's approval are included in Appendices L and M. Two participant information sheets were developed; one for the primary caregivers, and one for children. This ensured that in addition to primary caregivers, children were included in the decision making. The participant information sheets (Appendices H and I) and consent form (Appendix J) stated that participation was voluntary and would not affect the care their child received. Their right to withdraw from the study at any time without explanation or compromise to the child's care was also made explicit in both verbal and written information provided.

Confidentiality of the participants was ensured by removing all names from transcripts and drawings; a study number was provided, and pseudonyms were used when findings were presented. All data (both raw and electronic) generated from the research were managed and stored in line with requirements as set out by local and national research ethics guidelines (National Health and Medical Research Council, 2007 Updated May 2017). Hard copy data, including participant consent forms were kept in a locked filing cabinet at the study site in a secure office that is only accessible to the author and supervisory team. Electronic data, including scanned copies of the children's drawings and transcribed data, were secured on a hard drive specific for research data at Curtin University that is password protected and only accessible by the author and supervisory team. The digital audio recordings were erased from the audio recorder immediately following transcription and checking of data. All data will

be retained for seven years following completion of the project, in line with the requirements set out by the Western Australian Department of Health and Curtin University (Curtin University, 2015; Department of Health, 2012). All data will be destroyed following this period.

Measures to manage any unforeseen circumstances were made explicit prior to commencing data collection. It was determined that if the researcher identified that the child's condition had deteriorated following triage (such as reporting a high level of pain, which is causing undue distress), the clinical needs of the child would take precedence over data collection, and an ED staff member who could instigate the necessary care would be notified.

If during the follow-up interview stage, the child and/or primary caregiver became distressed, (such as the interview process prompting distressing thoughts or memories) the researcher would cease the interview and the researcher would initiate follow-up care required, which may include referring the child and family back to ED for further assessment. This was to enable referral to counselling, or any care necessary. Furthermore, to avoid any potential distress that may result from the researcher retaining children's drawings, all children were offered a copy of their drawing following the interview.



## **Chapter 5 Using ‘Draw, Write and Tell’ to Understand Children’s Health-Related Experiences: Learning with Children through Research**

The following is a copy of the final manuscript on the challenges and benefits of using DWT as a participatory research technique with children which was accepted for publication in the peer reviewed journal, *Nurse Researcher*. Aspects that affect data quality are discussed, which include the influence of the research setting and materials offered to children for the drawing activity. The role of primary caregivers in supporting their child to express their perspectives during the interview is considered. Establishing rapport with children through prolonged engagement and approaches to data analysis are also discussed. Copyright permission was obtained from the journal to include the manuscript in this thesis (Appendix N).

### **Reference:**

Pope, N., Tallon, M., Leslie, G., Wilson, S. (2018). Using ‘draw, write and tell’ to understand children’s health related experiences: Learning with children through research. *Nurse Researcher*, 29 (2) DOI: 10.7748/nr2018.e1594

## **5.1 Abstract**

In recognising the capability and rights of children to express their experiences, draw write and tell (DWT) has emerged as a participatory research method within the qualitative paradigm. Draw write and tell enables children to communicate their experiences by drawing, writing words and telling the story of their picture in response to interview questions. The authors reflect on the challenges and benefits of using DWT while exploring young children's pain experiences.

Aspects that affect data quality include the child feeling secure, influenced by the setting, the materials provided and presence of the primary caregiver. Primary caregivers need to be guided as to how to support their child without influencing the data. The duration of the interview is not important if trust between the child and researcher has been established. Data analysis will depend on the underlying philosophical framework of the research, however must ensure children's perspectives are not misinterpreted or lost.

## **5.2 Introduction**

A person's age should have little bearing on their ability to have a 'voice'. Beyond speech and language, the concept of voice includes nonverbal and emotional expressions a person uses to communicate their feelings and perspectives (Thomson, 2008). Health researchers interested in the experiences of children are often drawn towards participatory research methods as a medium of inquiry that recognises the capability of children to relate their health experiences. Examples of participatory methods include engaging children in creative activities to express their perspectives such as; drawings, scrapbooks, posters, collages, video diaries, and play (Carter & Ford, 2013). Those active in the fields of participatory research often adapt these methods and share their experiences to inform and guide future research. The aim of this article is to discuss the challenges and benefits of using the participatory research method, 'draw, write and tell' (DWT) (Angell et al., 2015), with children. The research materials, data quality and approaches to data analyses are examined. Insights are drawn from a recent experience using DWT in a study examining young children's (4-8 years) experiences of acute pain within the emergency department (ED) of an Australian tertiary paediatric hospital.

### 5.3 Background

Traditionally, research concerning children has adopted methods where inquiry was conducted *on* or *about* children. These methods call upon adults who have intimate knowledge of a child, such as caregivers or health professionals, to provide their insights into children's experiences; the children were not actively involved as research participants. Although seeking adult perspectives on issues involving children is sometimes necessary, what is meaningful to the children may not be captured (Angell et al., 2015). In recognising the limitations of research conducted *on* or *about* children, there has been a shift away from traditional research methods towards approaches that are undertaken *with* children where their perspectives are acknowledged and examined (Carter & Ford, 2013).

Research approaches undertaken *with* children examine the way children conceptualise their experiences and respect their capacity to provide expert testimony on issues that involve them (Sammons et al., 2016). In the same way that paediatric healthcare professionals have become aware of children's capacity to provide important information in clinical interviews, there is growing recognition among researchers of the contributions children's perspectives provide in research inquiry (Sammons et al., 2016). Because the world of experiences is a personal matter, research *with* children can collect unique insights that are otherwise unattainable or not considered by adults (Pain, 2012). Further, omission of children's perspectives may lead to researchers making inaccurate interpretations on issues involving children and in turn affect the credibility of findings (Angell et al., 2015).

Researchers who examine children's experiences are often guided by the fundamental rights of children to be consulted about, and express their views on matters that involve them. This notion stems from the United Nations' Convention on the Rights of the Child which aims to protect children from harm (United Nations, 1989). Researchers acknowledge the inherent ethical complexities faced in protecting children who participate in research. Issues such as the cognitive and developmental capabilities of children, as well as practical considerations can make involving children in research more complex compared with adults (Carter & Ford, 2013).

## **Drawings as data**

Drawing can be an enjoyable and therapeutic activity that captures children's interest and is an important tool to help develop early literacy and writing skills (Katz & Hamama, 2013). Drawing is a form of exploratory communication for children, particularly those yet to acquire linguistic fluency. Drawing stimulates children's imagination and can help them recall and express experiences (Carter & Ford, 2013). Furthermore, drawing provides an opportunity for children to articulate experiences that may be latent, less conscious and/or difficult to express through language alone (Pain, 2012). Similar to other participatory research methods, drawing provides a medium for children to contemplate questions they are asked rather than providing an immediate verbal response (Pain, 2012).

Draw and write (DW), and DWT are two examples of participatory research approaches that use drawings to investigate children's experiences. Draw and write has a history in the fields of psychology and education (Angell et al., 2015). Recently, researchers have embraced DW as a way to better understand children's views on health (Knighting, Rowa-Dewar, Malcolm, Kearney, & Gibson, 2011; Twycross & Finley, 2013). Draw and write involves children drawing a picture(s) and writing words in response to interview question(s). Data analysis is conducted on the children's written words and drawings. As part of the analysis process, some researchers also examine elements within the drawings like shapes, lines and colours (Katz & Hamama, 2013). A recent review of the literature found ambiguity and inconsistency regarding analytical processes applied by researchers using DW; while some analysed the children's drawings others did not clearly report their analysis process (Angell et al., 2015). A limitation in analysing children's drawings is that when adult researchers apply their interpretations of drawings, the perspectives of the child may be misinterpreted or lost. Recently, DWT emerged as a practical solution to these dilemmas.

Similar to DW, DWT requires minimal resources, and involves asking children to draw a picture(s) and write words in response to interview question(s). As an extension of DW, the 'tell' element makes up the data to be analysed. Children are asked by the researcher to describe what they have drawn, and these narratives are recorded and transcribed. Therefore, a child's own interpretation of their drawing is captured in the

transcript. The drawings are not subject to analysis, assuring that children's interpretations of their drawings are represented (Angell et al., 2015).

Evidence shows that young children are capable of expressing subjective concepts such as their pain experiences to others (Pope, Tallon, McConigley, Leslie, & Wilson, 2017b). The way children experience and express pain is influenced by factors such as previous pain experiences, expectations of pain, a child's developmental and linguistic abilities and sociocultural factors (Pope et al., 2017b). Using language alone is unlikely to capture the multifaceted layers of the younger child's pain experience. Offering children the opportunity to draw provides them a means to express various aspects of their pain that may be difficult to articulate.

#### **5.4 Challenges and Benefits of Draw, Write and Tell**

Draw write and tell offers a means of data collection and analysis that includes visual, verbal and environmental cues rather than relying on verbal transcripts or pictures alone. The following explores the challenges and benefits of applying DWT and draws on the authors' experiences of using the method with children.

##### **Data collection and quality**

Similar to clinical care, consideration needs to be given to the research setting and who is present during the interview to ensure participant comfort and privacy, as these can influence data collection. To minimise the influence of psychological attachment, researchers can speak with primary caregiver(s) about their role in interviews prior to commencing data collection (Priddis & Howieson, 2012). By providing clear information related to what can be done to support their child in expressing their perspectives, the meaningfulness of data can be preserved. Additionally, establishing rapport with the child before beginning data collection helps them to feel comfortable in sharing their experiences (Angell et al., 2015). In our study, this took up to 40 minutes as a form of prolonged engagement. Lincoln and Guba (1985) advocates prolonged engagement as a quality enhancement strategy providing both credibility and authenticity in qualitative inquiry.

Consideration is also required about the materials provided for the drawing activity, such as drawing and writing instrument(s), as well as the size and type of paper. These

materials can influence the drawings created by children, the data quality and ultimately, the findings. Further, studies using DW or DWT often omit detail related to the materials used for the drawing activity (Angell et al., 2015). Choice provides children with a sense of control (Carter and Ford, 2013), therefore in our study children were provided 12 coloured pencils for the drawing activity. Providing a range of colours is also important in exploring children's pain experiences as younger children can use colour as a way to express various characteristics of their pain as well as their emotional responses (Knighting et al., 2011). This was evident in our experience where similarities were noted in relation to the colours chosen by children to represent aspects of their pain. For example, red was a common colour children chose to represent blood, painful sensations and fear. As a way to better understand children's experiences, the researcher asked children to explain the choice of colours they used in the drawing. In this way any relevance of colour was captured in the dialogue that made up the transcripts for analysis. An example from our study is a drawing created by one young boy (see Figure 5.1).



**Figure 5.1** Drawing created by a seven year old child

The red shading on the right of this drawing was reported by the child to depict his injured finger, the green on the right represented his uninjured finger (Used with permission HREC No: 2014082EP).

The size and type of paper provided to children also contributes to optimising the quality of verbal data for analysis. While the use of a paper square, (10 x 10 cm) called

'iSquares' are appropriate for adults (Hartel, 2014), the small piece of paper and the ten minute data gathering would not be appropriate for young children. In our study children were offered A3 sized paper to accommodate their gross and fine motor skills. The top section of this paper was blank, and the bottom had ruled lines for the children to write words to express their experiences. So that these words could be included in the transcripts, the children were asked to read out and explain what they had written. The size and layout of the paper also captured children's interest and offered a generous area for drawing.

The semi-structured interview began when the child was asked to draw a picture representing their pain experience, and audio-recording commenced at this time. All verbalisations were transcribed for inclusion in the analysis process. If the child asked questions or explained what they were drawing, this too was included in the transcripts. When the child finished drawing, they were invited to write words and tell their story. This process lasted between five to twenty minutes. Despite the brevity of some interviews, the drawings meant some children required few words to portray their experience. This was exemplified in the story shared by a child who spent ten minutes silently drawing. When asked by the researcher to describe what had been drawn, the child explained that it was a 'TNT', and their pain was like '*a bomb*'. While TNT as a word alone may not represent depth of data, the surety in how it was expressed captured in the field notes supported that for this child, his pain experience included a range of sensory dimensions. Here, drawing provided a means to express elements of pain that may have otherwise been difficult to articulate. This highlights that interview duration is not a determinant of the quality of the data generated, but rather attention to allowing for prolonged engagement, consideration for the research setting and materials used.

### **Approaches to data analysis**

Draw, write and tell can be adapted to a range of analysis techniques dependant on a study's underpinning philosophical framework and/or the research question(s). It is important that the approach to data analysis is clearly documented so readers can assess trustworthiness. For example, the constant comparison technique of grounded theory can offer researchers a systematic process to analysis, which directs the researcher back to the data and forward into the analysis to refine emerging themes

(Hussein, Hirst, Salyers, & Osuji, 2014). Similarly, content analysis applied to transcribed data can offer a systematic approach to quantify and group data into themes (Holloway & Wheeler, 2010).

Thematic analysis, as described by Braun and Clarke (2006) was undertaken in our study. Using an inductive approach transcriptions were examined, codes were created and grouped, and emergent themes identified. Analysis was driven by the data rather than the researcher's analytical or theoretical interest. This approach offers insights into experiences individually rather than being guided deductively. In our study, children's drawings were not subject to analysis, instead drawings were used as a medium for children to explain their perspectives. This safeguarded against the researcher providing adult interpretations of the children's drawings (Angell et al., 2015). Thematic analysis offered a flexible and rigorous approach to analysis, where the researchers moved through the process of discovery, and examined beneath the surface to produce insights into participants' experiences (Braun & Clarke 2006).

Analysis of the drawings may be considered, however, skills in analysing artwork are required to ensure robustness. If drawings are analysed, there needs to be constant reference to the participant's interpretations of their drawing, and the context in which the drawing was created (Angell et al., 2015).

Reflexivity, the process by which researchers adopt a critical stance to reflect on their involvement in a study, is essential to the qualitative paradigm. It allows researchers to locate themselves in the project and consider how they may influence the study (Holloway & Wheeler, 2010). In our study, alongside maintaining a reflexive journal to enhance researcher credibility (Lincoln & Guba, 1985), field notes were maintained. These notes included unspoken behavioural aspects such as the children's expressions, body language and/or positioning in relation to their primary caregiver. These observations included important details of the children's experiences. Notable in our study was the behaviour of one child, who initially sat beside her mother, but moved to her lap when she began to speak about her pain. Another child looked to his mother for reassurance and reached for her hand while sharing his pain experience. The need for security demonstrated by the actions of these children were captured in field notes.



## 5.5 Implications for Practice and Research

The use of DWT can extend to a variety of contexts, including research with adults. The DWT has potential for use in examining experiences of participants with limited language proficiency, those with cognitive deficient or people with mental health concerns. The DWT may also be incorporated as a form of data triangulation. Future studies could examine the potential of incorporating drawings as an information-sharing tool in adult and paediatric clinical settings.

## 5.6 Conclusion

There has been a move towards conducting research *with* children rather than *on* children. This emphasis is placed on acknowledging the capability and rights of children to have a voice on issues that involve them and explore their experiences. Research methods such as DWT have emerged as an approach that enables children to engage in research and share their perspectives in ways that suit their developmental abilities. Using DWT allows children to share their experiences in a non-intimidating inclusive manner. Drawing offered children access to a natural alternative language, which seemed to help them express their experiences.

Reflecting on our experience of using DWT highlighted various challenges and benefits when applying this method with children. These included the influence of the primary caregiver(s) on data quality, as well as the importance of prolonged engagement, the research setting, and materials used. Guided by research questions and underpinning philosophy, the researchers' approaches to data analyses were also considered. Practical and speculative recommendations were presented for consideration including the need to inform primary caregiver(s) of their role in supporting their child to express their perspectives and spending time to build rapport before data collection. Providing a range of coloured pencil options helps children feel a sense of control. Colours may also enrich data, while field notes contribute to data analysis. Regardless of the approach selected it is essential that children's perspectives are preserved.

## **Acknowledgements**

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## **Declaration of conflict of interests**

The authors declare that there are no conflicts of interest.

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## *Chapter Summary*

The DWT technique is a participatory approach to data collection that offers an appropriate and useful means to examine children's experiences. This chapter presented the challenges and benefits of using the DWT method with children. Factors that affected data quality included the child feeling secure, influenced by prolonged engagement and the presence of primary caregivers; as well as the research setting, and materials provided. Data analysis was also considered and identified that the approach taken will depend on the research question and the underlying philosophical framework which must ensure that children's perspectives are not misinterpreted or lost. Whilst each participating child embraced the opportunity to draw and talk of their experiences, it is acknowledged that this may not be the case for all children.

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## **Chapter 6    Ask Me: Children’s Experiences of Pain Explored using the ‘Draw, Write and Tell’ Method**

Results of the qualitative descriptive study using the DWT technique to explore children’s pain within the ED are presented in this chapter in the form of a manuscript accepted for publication in a peer reviewed journal, The Journal for Specialists in Pediatric Nursing. Copyright permission was obtained from the journal to include this manuscript in the thesis (Appendix N). As it is a manuscript of the original study, there is some repetition of the methods presented in Chapter 4.

### **Reference:**

Pope, N., Tallon, M., Leslie, G., Wilson, S. (in press). Ask me: Children’s experiences of pain explored using the draw, write and tell method. *Journal for Specialists in Pediatric Nursing*

## **6.1 Abstract**

### **Purpose**

Pain management within emergency departments (ED) remains challenging. Given that unrelieved pain in children is linked to a number of negative physiological and psychological consequences, optimal management of children's pain is paramount. Many studies exploring children's pain have adopted quantitative methods or sought the perspectives of adults. Compared to adults, studies examining children's views on pain and pain management are limited. This study aimed to explore children's pain experiences, their perception of pain management and expectations of the role of the nurse.

### **Design**

This was a qualitative descriptive study using an inductive approach.

### **Methods**

Fifteen children aged four to eight years who presented to the ED of an Australian tertiary paediatric hospital in acute pain participated. Data were collected using draw, write and tell (DWT) technique and analysed using thematic analysis

### **Results**

Three themes emerged: 1) 'Security', 2) 'My pain' with subthemes: 'The pain feelings' and 'My sad/happy feelings', 3) 'Comfort and relief' with subthemes: 'Taking my mind off it', 'Resting' and 'Hospital things'. When in pain children needed to feel secure. Parents and nurses were important in fostering a secure environment for children. Children were capable of describing their pain and identified non-pharmacological strategies to help their pain.

### **Practice implications**

Children as young as four years old can provide detailed accounts of their pain, which extends beyond physical dimensions to include visual, auditory and sensory features. Nurses need to listen, be honest, and develop trust with children to be helpful. Non-pharmacological pain relieving strategies can be implemented by parents and nurses in collaboration with the child. Fostering a secure environment is essential.

## **Search terms**

Draw, write and tell, pain, children, emergency department, paediatric, qualitative.

## **What is currently known?**

Pain management within emergency departments is challenging. Pain in children is multifaceted, complex and subjective. Effective assessment and management relies on a comprehensive, multimodal approach inclusive of the biopsychosocial factors that influence a person's pain experience. Given that unrelieved pain in children is linked to a number of negative physiological and psychological consequences, optimal management of children's pain is paramount. Compared to adults children's views on pain and pain management are scarce.

## **What does this article add?**

Children as young as four years old are capable of giving detailed accounts of their pain experiences. Children can identify positive and negative aspects of care that contribute to their pain experience. Greater attention to the therapeutic use of non-pharmacological strategies is needed by supporting children to engage in activities that they enjoy to help take their minds off their pain. The draw, write and tell (DWT) technique allows children to express aspects of their pain which may have been difficult to articulate using language alone.

## **6.2 Introduction**

Pain, and its management is a major aspect of the care provided in hospital emergency departments (ED), with up to 78 per cent of patients reporting pain among their symptoms on presentation (Australian Institute of Health and Welfare, 2016). In 2015–16, there were nearly 7.5 million presentations to EDs across Australia of which 22 per cent accounted for children under 15 years of age (Australian Institute of Health and Welfare, 2016). Despite a commitment by healthcare professionals to adequately manage pain, children continue to needlessly experience pain as a result of ineffective management (Harrison et al., 2014; World Health Organization, 2012). There is evidence linking unrelieved pain in children to a number of short and long-term behavioural, physiological and psychological problems (Fegran, Ludvigsen, & Haraldstad, 2014). Optimal management of children's pain is therefore of utmost

importance. Given that pain is a multifaceted, complex, subjective phenomenon, effective management relies on a comprehensive, multimodal approach inclusive of the biopsychosocial factors that influence a person's pain experience (Pope, Tallon, McConigley, Leslie, & Wilson, 2017). Despite this knowledge, evidence suggests that healthcare professionals, most of which are nurses, tend to focus on the physical aspects in pain management (Rolin-Gilman, Fournier, & Cleverley, 2017).

In ED settings factors such as urgency of medical treatment, overcrowding, uncertainty related to waiting periods, and inaccurate recognition of pain by staff, all contribute to ineffective and inconsistent pain management (Ortiz, López-Zarco, & Arreola-Bautista, 2012; Scott, Crilly, Chaboyer, & Jessup, 2013). Inadequate pain score documentation has also been linked to poor pain management practices in paediatric settings (Twycross & Collis, 2013). A plethora of research related to paediatric pain management exists. Many of these studies have adopted quantitative methods, and while results of these studies have made important contributions to the management of children's pain, relying largely on quantitative methods risks missing the experience of pain from the child's perspective (Pope, Tallon, Leslie, & Wilson, 2017; Twycross & Finley, 2013).

Few published studies have captured children's experiences of pain within the ED. Two cross sectional studies examined children's (7-18 years) pain experiences in ED (Parra, Vidiella, Marin, Trenchs, & Luaces, 2017; Weingarten, Kircher, Drendel, Newton, & Ali, 2014). A survey was used to capture children's experiences of pain and pain management in a Canadian ED (Weingarten et al., 2014), while the other study sought children's experience of pain management as part of their overall experience in a European ED (Parra et al., 2017). Pain management in the European ED was rated poorly by the children (Parra et al., 2017) in contrast to those in the Canadian ED who were satisfied despite most having pain on discharge (Weingarten et al., 2014). The children's satisfaction was associated with effective communication between the child and healthcare professional and when the medication worked quickly (Weingarten et al., 2014). In addition to seeking children's views, the European study sought the perspectives of the parents, who also rated pain management poorly. Because parents completed the survey at the same time as their child, there is potential that the parents influenced their child's response.

These divergent results indicate that further exploration is required. A deeper understanding of children's pain may be offered by qualitative research aimed at exploring the experiences through the eyes of participants (Pope, Tallon, Leslie, et al., 2017). To our knowledge, no study has been undertaken to explore children's experiences of pain within the ED using the draw, write and tell (DWT), which allows children to share their views in a manner that best suits their cognitive development (Angell, Alexander, & Hunt, 2015).

The DWT technique invites children to draw pictures and write words in response to questions. Then the central aspect of data collection involves the researcher asking the children to explain their drawing and any words they have written. Therefore, a child's own interpretation of their drawing is captured, and these narratives are recorded, transcribed and analysed. When using DWT, the children's drawings are not subject to analysis, assuring that children's accounts of their drawings are represented (Angell et al., 2015). For example, content analysis was applied to the transcripts of children with ADHD examining what makes life good for them (Barfield & Driessnack, 2018), while a thematic framework was used to analyse the transcripts of school age children's views on physical activity (Noonan, Boddy, Fairclough, & Knowles, 2016). Further details of the DWT technique have been published previously (Pope, Tallon, Leslie, & Wilson, in press). Draw, write and tell offers an engaging approach to examine the children's pain experiences and was used to explore children's perceptions of their pain and the pain management they received while in the ED. Children's expectations of the role of the nurse in pain management were also explored.

## **6.3 Methods**

### **Design**

A qualitative, descriptive study using an inductive approach was undertaken.

### **Setting and sample**

Children aged four to eight years presenting with acute pain to the ED of a paediatric tertiary hospital in Australia were eligible to participate. The ED accepts children from birth to 16 years of age, and has approximately 65, 000 presentations each year (Australian Institute of Health and Welfare, 2017). Children who could understand and

speak English, had no cognitive deficit and did not require urgent medical treatment were eligible. Convenience followed by purposive sampling were used to ensure the capture of a range of pain aetiologies. Sample size was determined by the completeness of data; data collection continued until saturation was reached. Fifteen children (11 males and four females) participated. Eleven of the children had not previously presented to an ED for treatment. Most children had non-complex medical histories, except for one child. Participants' characteristics and the range of pain aetiologies are presented in Table 6.1.

**Table 6.1 Characteristics of participating children**

<b>Name*</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Principle diagnosis</b>	<b>**LOS (hours)</b>	<b>Treatment received in ED</b>
Ben	5	Male	Lacerated scalp	3	Topical analgesia Staples Wound dressed
Caitlin	5	Female	Bilateral otitis media	1.5	Oral analgesia
Cathy	8	Female	Fractured radius	1.5	Oral analgesia Sling fitted
Edward	7	Male	Ear infection and vomiting	6	Oral analgesia Bloods drawn X-ray
Henry	5	Male	Blunt head injury	1	Monitored
Isabella	4	Female	Fractured radius	2	Oral analgesia X-ray Wrist splint
Logan	7	Male	Abdominal pain	1.5	Urinalysis
Mike	5	Male	Fractured toe	2	X-ray
Molly	7	Female	Chin laceration	1.5	Oral analgesia Wound glued Wound dressed
Nelson	5	Male	Fractured radius	1	Plaster fitted
Ryan	7	Male	Soft tissue injury	2	Oral analgesia X-ray
Sam	6	Male	Soft tissue injury	2	X-ray
Spencer	8	Male	Soft tissue injury	1.5	X-ray



<b>Name*</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Principle diagnosis</b>	<b>**LOS (hours)</b>	<b>Treatment received in ED</b>
Thomas	5	Male	Irritable hip	3	Oral analgesia X-ray Bloods drawn
Toby	6	Male	Periorbital cellulitis	4	Intravenous cannula Intravenous antibiotics

Note: \*participant names were replaced with pseudonyms to assure anonymity. \*\*Length of stay.

## **Procedure**

A stakeholder group was established to determine the research questions and inform recruitment and data collection processes. The stakeholder group was made up of three senior paediatric nurses with clinical experience in the ED, a research fellow and a consumer representative who was a parent with young children. Three meetings were held with ED staff to ensure they were informed of the study and recruitment procedure.

Recruitment and interviews took place from May to September 2015. This occurred following triage and prior to receiving treatment and did not delay the child's clinical assessment and intervention. Details of the study were discussed with the primary caregiver and child and written information was provided. Informed consent was obtained from primary caregivers who agreed for their children to participate in the study and assent was obtained from the children who were able. All identifying information were removed from the data and pseudonyms used to maintain confidentiality. Research ethics approval was granted by the participating hospital (ref 2014082EP) and the authors' affiliated university (ref HR46/2015).

## **Instrument**

The interview questions (Table 6.2) were adapted from two previous studies examining children's experiences of postoperative pain (Sng et al., 2013; Twycross & Finley, 2013). The questions were examined in terms of the research objectives by members of the stakeholder group.

**Table 6.2 Interview Questions**

Num	Interview Question
1	Draw a picture about how you felt when you were in pain.
2	Are there any words you would like to write about how you felt when you were in pain? (I can help you with writing)
3	Tell me about the picture and the words you have written
4	What made the pain feel better/go away?
5	What did nurses do when you were hurting?
6	What do you think nurses should do to help your pain feel better?

*Note.* Questions 1-3 adapted from "Children's and parents' perceptions of postoperative pain management: a mixed methods study," by A. Twycross and G.A. Finley, 2013, *Journal of Clinical Nursing*, 22(21/22), p.3095  
Questions 4- 6 adapted from "Postoperative pain management experiences among school-aged children: a qualitative study," by Q. W. Sng et al. 2013, *Journal of Clinical Nursing*, 22(7-8), p.958.

Demographic details including the child's date of birth and gender were collected. In addition, clinical details related to the source of the child's pain, the child's pain scores on admission and discharge, and the medical treatment provided in the ED were collected from the child and hospital case notes following discharge from the ED.

### **Data collection**

The children's experiences were collected using the DWT technique. Semi-structured interviews were conducted in a location that was convenient for the children and their families and took place within 48 hours of ED discharge while the pain experience remained recent. All children were accompanied by their primary caregiver(s) who were the child's mother (n=13) or father (n=2). Interviews were conducted in participant's homes (n=6), a local park (n=2), a local café (n=2) or a quiet, non-clinical area in the hospital (n=5).

Following a period of prolonged engagement (Lincoln & Guba, 1986) (range of time from 45mins to 2 hours) rapport was developed between the child and the researcher. The interview began by asking the child to draw a picture which represented their pain. Audio recording commenced at this time. The child was then invited to write words and talk about their pain experience by explaining their drawing.

Although children were able to take as long as they required to draw, write and tell their story, interviews ranged between five and 17 minutes in duration and were carried out by the researcher (NP) who was not involved in direct patient care. Field notes

were maintained to capture contextual details and non-verbal interactions observed by the researcher during the interviews. Reflexive notes were also recorded. As a paediatric nurse and a mother of a toddler, it was very important for the researcher to locate herself in the project and examine any potential biases that may have influenced the study. All interviews were transcribed verbatim.

### **Analysis plan**

Transcripts were subject to thematic analysis as described by Braun and Clarke (2006). Codes were identified and named following examination and re-examination of the transcripts. Similar codes were grouped together, and themes emerged. The process of coding and grouping of codes was undertaken independently by two researchers (NP and MT) then recorded and illustrated using a thematic tree (Figure 6.1). Coded data and groups were examined, and emergent themes identified and discussed with the research team until agreement was reached. Only the transcripts were subject to analysis, while the drawings were used to guide enquiry during the interview (Angell et al., 2015; Pope et al., in press). A decision trail for auditing purposes was maintained. Data were managed using nVivo10 software (QRS International, 2014).

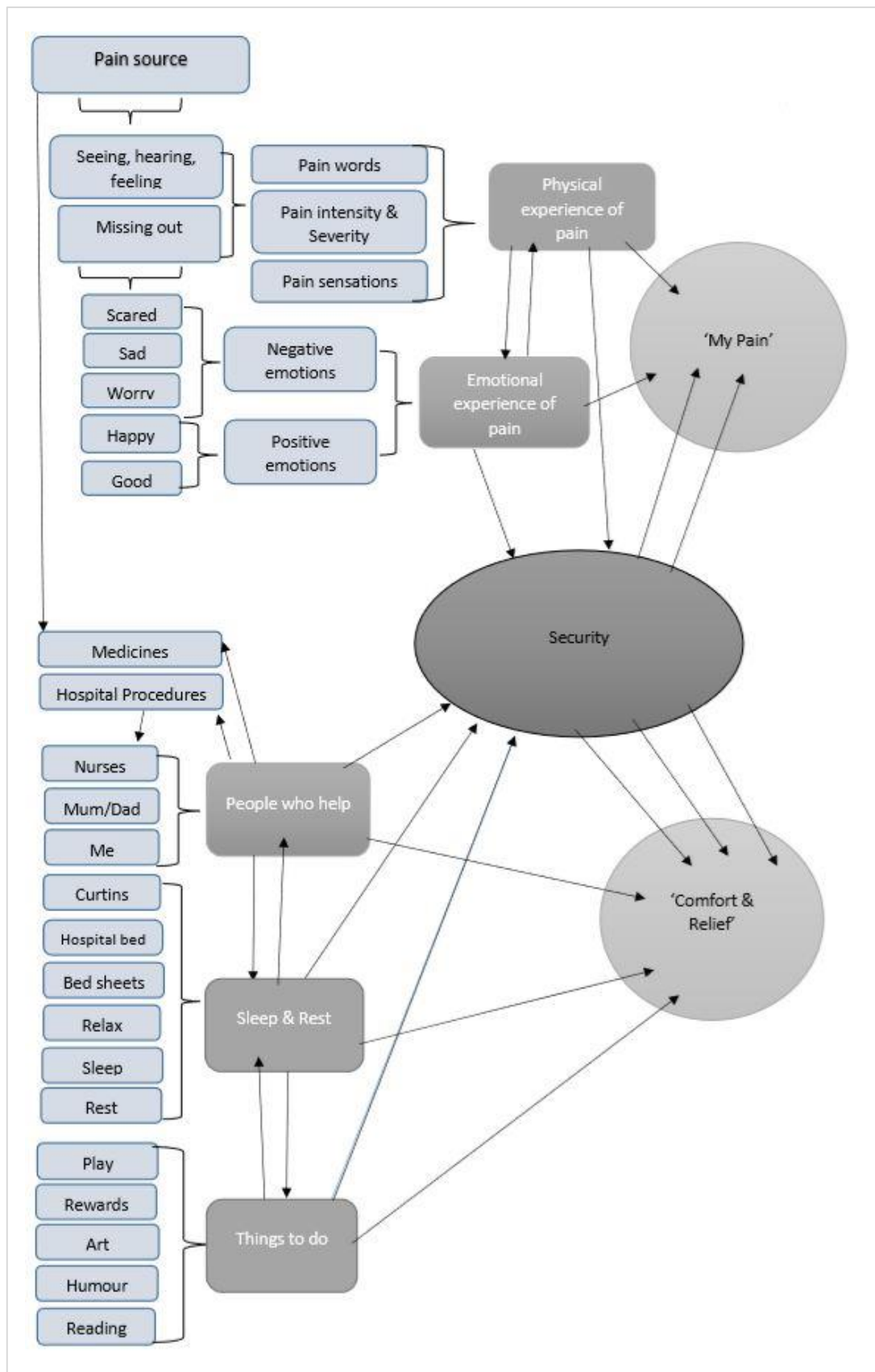


Figure 6.1 Thematic tree

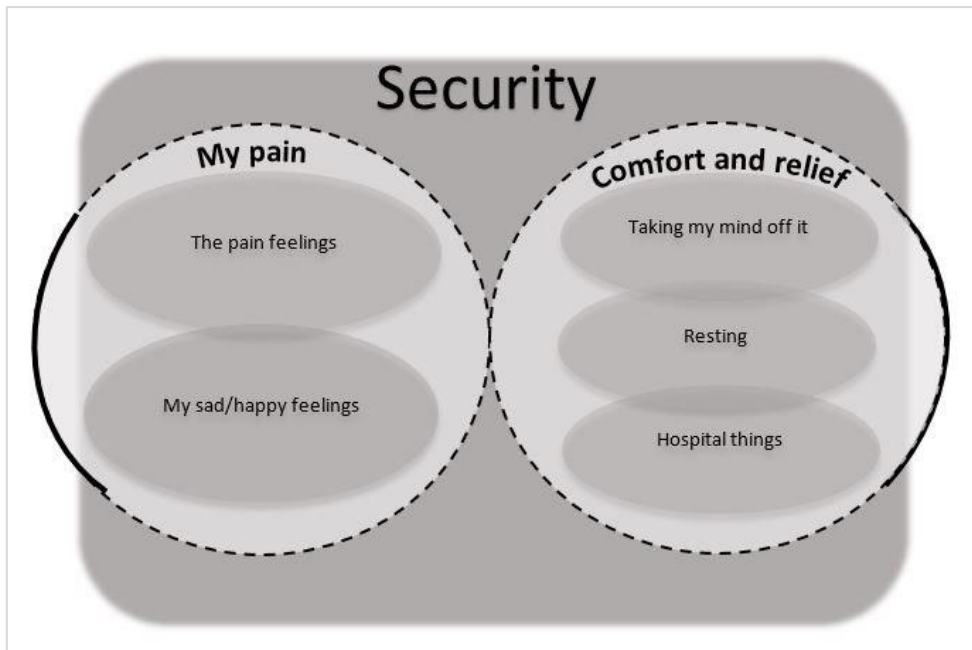
## **6.4 Results**

### **Drawings**

All children drew, wrote and told stories about their pain, and every child included a version of themselves in their drawing. Thirteen drawings were of the child alone and two included the child's primary caregiver. Only one child included a healthcare professional (doctor) in his drawing. In nine of the drawings children represented where they felt pain, which was most commonly drawn in red or black. Two children drew themselves in the hospital, two drew themselves at the site where their injury had occurred, and two children depicted themselves in both the hospital and at the site of their injury.

### **Themes**

A conceptual framework (Figure 6.2) was constructed from three main themes that emerged from the data. The first main theme named 'Security', was found to be essential to the other two main themes whereby the children's pain experiences were expressed only in the context of feeling secure. The second main theme was named 'My pain' and the third was named 'Comfort and relief'. The second main theme 'My pain' included two subthemes 'The pain feelings' and 'My sad/happy feelings'. The third main theme 'Comfort and relief' included three subthemes named, 'Hospital things', 'Taking my mind off it' and 'Resting'. While the second and third main themes 'My pain' and 'Comfort and relief' were reliant on the first main theme 'Security', they were found to be independent of each other. The subthemes, 'The pain feelings' and 'My sad/happy feelings' were interconnected within the second main theme 'My pain'. Likewise, the subthemes 'Taking my mind off it', 'Resting', and 'Hospital things', were found to be interrelated within the third main theme 'Comfort and relief' (Figure 6.2).



**Figure 6.2** Conceptual framework

### *Security*

While children experienced pain, they needed to feel secure. All children relied on the presence and actions of their parents to feel secure within the hospital environment. Most of the children expressed a desire to be with their mother when they had pain. One child needed his father. None of the children mentioned the need for other family members or friends. All children expressed feeling secure when with their parent;

*Like a kangaroo – hugging my mummy*

(Thomas, age 5 years)

Further, every child relied on the caring actions of their parent to help them feel secure. Gestures such as holding their hands, rubbing or holding where it hurt, talking to them, giving pain relief medication or gifts, providing food or drink, and playing games together were identified. Most children also relied on their parents to explain procedures and treatments. Some children described how they were cared for by their parent;

*Some mornings my mum put it [medicine] in my mouth*

(Caitlin, age 5 years)



**Figure 6.3** Caitlin's drawing

Caitlin reported that the figure on the right of her drawing represented herself and the figure on the left represented her mother (Figure 6.3).

In addition to parents, the actions and presence of hospital staff, such as nurses, doctors and hospital clowns helped foster an environment where children felt secure. Children identified that being read to, having things explained to them, being tickled or massaged were actions nurses did, or could do, that helped their pain and also fostered a sense of security. These actions were identified in the experiences of some children and expressed as activities nurses could do to help by other children. Physical actions such as lying on the hospital bed, being covered with blankets and having the curtains drawn, were also identified as important to contribute to their sense of security. Although there was no bed in Thomas' drawing, he told of the importance of the bed in helping him feel secure;

*My toes and the bed.....I could tickle the bed...hugging the bed*

(Thomas, age 5years)

Feeling secure allowed children to share their experiences. This was observed in the behaviours of children during the interviews and noted by the first author. All children were positioned next to their parent, many looked to their parent for reassuring verbal

prompts, and some sat on their parent's lap while they spoke about their pain. All children referred to their primary caregiver when talking about their pain experience, and two children included their primary caregiver in their drawing.

### *My pain*

'My pain' included the children's experience of the physical and emotional aspects of their pain.

### *The pain feelings*

All the children pinpointed the locations of their pain and described physical sensations related to their pain. Children were also able to detail elements of severity, depth and intensity of the pain. All children used descriptive words to characterize their pain. Examples of these included; *stinging, sore, sharp, bad, hurts very much, a lot hurting, quite strange, and uncomfortable*. Concrete thought processes were reflected in younger children's expressions;

*I felt like my leg was broken*

(Thomas, age 5 years)

For Thomas the source of his pain was not physical injury or trauma, but a self-limiting inflammatory condition, transient synovitis (also known as irritable hip), however, his narrative reflected the severity of his pain. Some children detailed sensations related to the intensity of their pain in keeping with their understanding of the world. For one older child, pain sensations were widespread rather than localized;

*It felt like hmmm, I ran into a TNT*

(Spencer, age 8 years)

The impact of how the sight of blood contributed to the experience of pain was both identified in the transcripts and featured in one child's drawing and writings;

*It was about the blood. A lot of blood flooding the steps of blood.  
Then there was blood coming all over those steps*

(Ben, age 5 years)





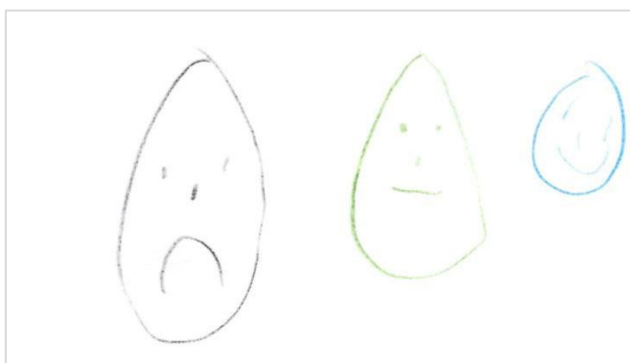
**Figure 6.4 Ben's drawing**

Ben reported that the red shading on the right of his drawing depicted the step where the injury occurred and represented his blood loss (Figure 6.4).

*My sad/happy feelings*

All children expressed negative emotional responses associated with their pain, including; *sad, angry, confused, bad, nervous, a little bit grumpy, not very good, shocked, and scared.*

Sam, age six years, shared how his emotions changed from very sad to normal and happy as his experience of pain diminished (Figure 6.5).



**Figure 6.5 Sam's drawing**

Logan, despite confidence and familiarity with the hospital because of several previous admissions, shared feelings of sadness represented verbally and, in his drawing (Figure 6.6).



**Figure 6.6** Logan's drawing

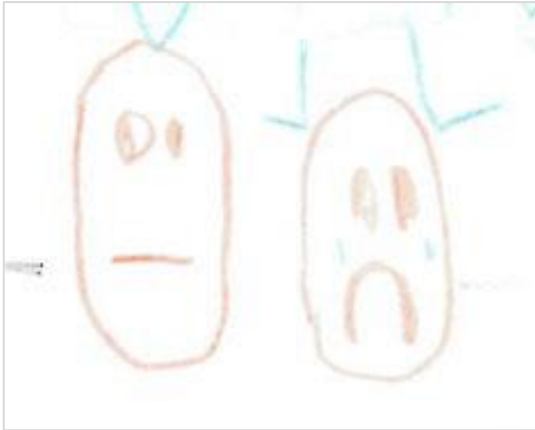
*I felt sad*

(Logan, age 6 years)

For most children, feelings of sadness about not being able to play, do sport, or go to school because they had pain were shared. One child identified his mother's feelings of sadness because he had pain;

*My mum feeled a bit sad, and I was being ok*

(Nelson age 7 years)



**Figure 6.7 Nelson's drawing**

Nelson reported the feature on the left of his drawing represented himself feeling 'ok', with his mother on the right who was 'sad' (Figure 6.7)

Few children identified positive emotional responses such as feeling; happy and good. However, when expressed, these feelings were associated with children having completed medical treatment, leaving the ED, or when their pain was gone;

*Happy. When I am about to go it doesn't hurt*

(Mike, age 5 years)



**Figure 6.8 Mike's drawing**

Mike reported his drawing represented himself feeling 'happy' just prior to being discharged from the ED (Figure 6.8).

### *Comfort and relief*

This theme included the children's perspectives about their need for various forms of comfort to help them when in pain. All children identified a range of strategies they found effective in managing their pain. Some children were able to self-initiate these comfort strategies, however, most relied on primary caregivers and nurses to initiate these strategies for them.

### *Taking my mind off it*

All children described various forms of distraction they found helpful, such as drawing, doing puzzles, playing computer games or watching television;

*Go on screens. Like, I would get distracted on it, so I wouldn't feel the pain*

(Spencer, age 8 years)

Some children shared the benefits of food and drink, going outside, and receiving rewards such as confectionaries, toys, stickers and stamps. Other children also described humor as important, laughter brought comfort to the children;

*Well the clowns did [help the pain] they made me laugh*

(Thomas, age 5 years)

### *Resting*

Some children expressed a desire to rest as an important measure in helping them when they had pain. Children relied on hospital staff, mainly nurses, and their parents to help them to rest;

*When you rest, you will feel better*

(Nelson, age 7 years)

### *Hospital things*

Most children described medicines (oral, topical and intravenous) as well as care practices including; plaster casts, bandaging, and applying heat or cool packs as effective in relieving their pain. Some children also recognized that while blood tests, x-rays and needles added to their pain, these were necessary procedures undertaken by nurses to help them when they had pain. Most children were familiar with the names

of pain relief medication. Some children reported that medicines were not always completely effective in treating their pain;

*When they put the numb [topical anesthetic] on. It worked but then it didn't work. They [nurses] didn't put the one that worked on me, they put a different one*

(Ben, age 5 years)

## **6.5 Discussion**

This study explored children's perceptions of their pain and pain management within the ED, as well as their expectations of the role of the nurse in helping to relieve pain. Security was found to be essential to children's experiences and enabled children to express detailed accounts of their pain that included physical, emotional, and sensory dimensions. Children also identified a range of factors that helped with their pain and described non-pharmacological strategies such as engaging in activities and resting their bodies as effective measures of relief. Nurses who listened and engaged in distraction activities such as reading and playing games were identified as helpful. Parents and nurses play an important role in supporting non-pharmacological approaches to pain management and a secure environment for coping with pain.

Children relied on the presence and nurturing actions of a parent to help foster a sense of security when they had pain. In the context of this study a sense of security is associated with protective factors including parental warmth, competency, coping skills, and behavioural responses (Rothbaum, Kakinuma, Nagaoka, & Azuma, 2007). The consistent presence and responsiveness of a primary caregiver has also been shown to promote positive psychological outcomes in children when they have pain (Barone et al., 2016). Furthermore, it is well understood that relational and physical aspects help foster a secure attachment, and the affectional bond between a child and their primary caregiver contributes to children feeling secure in times of stress and threat (Bowlby, 1969). Conversely, in the absence of primary caregiver(s), a child's pain and distress is exacerbated (Pope, Tallon, McConigley, et al., 2017).

In this study all children responded positively to the request to create a drawing and were able and willing to provide detailed accounts of the physical sensations related to their pain. Affective and evaluative words were used to describe the intensity, depth,

and severity of their pain. Young children's expressions of their pain were in definitive terms, while older children were able to relate their pain to their experience of the world which was demonstrated in the story shared by one child who drew a 'TNT' and described that his pain was like 'a bomb'. These findings support existing evidence where children's descriptions of pain follow a pattern of increasing abstraction in line with their cognitive development (Esteve & Marquina-Aponte, 2012).

Alongside the physical dimensions of pain, aspects of the visual, auditory, and tactile sensory processes were also reflected in the findings. For one child, the sight of his own blood was the dominant feature of his drawing, for another child the pain experience was described as an explosion. This highlights how external sensory processes such as sights and sounds influence pain perceptions (Benuzzi, Lui, Duzzi, Nichelli, & Porro, 2008; Price, 2000). In keeping with this, visual cues associated with pain, such as blood and the sight of painful procedures or injections, have been shown to activate brain regions involved in processing pain which heightens the pain experience (Benuzzi et al., 2008; Ogino et al., 2007) and increases anxiety. This draws attention to the importance of minimizing children's exposure to noxious stimuli often common in the hospital setting. This is relevant to healthcare professionals working in EDs where painful procedures are undertaken with greater urgency, and in particular mixed EDs where the physical environments are not tailored exclusively to the care of children.

In addition to supporting the physical features of pain, it is well understood that pain is also an emotional experience. While this is widely acknowledged in research findings (Pope, Tallon, McConigley, et al., 2017) it is less appreciated in practice, where pain and its management are often addressed from the physical perspective (Rolin-Gilman et al., 2017). In this study, children shared negative emotional responses to their pain, which included feelings of fear, sadness, and apprehension about being in pain. Children expressed understanding of the consequences of their pain, in terms of missing out on activities they enjoyed, or not playing with friends, also contributed to their negative emotions. These findings resonate with those of Cheng, Foster, Hester, and Huang (2003) who reported that children felt there was nothing positive about their pain and some children even associated their pain with death. Further, it has been identified that children experience negative emotional responses as a result of their anticipation of pain (Wen, Taylor, Lixia, & Hong-Gu, 2013). Emotional responses have been shown not only to exacerbate and intensify

pain, but also lower a child's pain threshold (LeMay et al., 2010). These findings highlight the need to consider assessment and interventions that go beyond addressing physical symptoms of pain to include the complex interplay of emotional factors (Vetter et. al., 2013).

As with children's accounts of their pain, visual, auditory and tactile processes were helpful for children when they had pain. The effectiveness of non-pharmacological interventions was evident where engaging in visual activities such as cartoon viewing, playing video games, drawing, or going outside helped children with their pain while providing a means of distraction from visual noxious stimuli. Resting was also reported by the children as important. These findings are in keeping with evidence that supports the integration of non-pharmacological pain modalities as essential in alleviating children's pain (Woragidpoonpol, Yenbut, Picheansathian, & Klunklin, 2013). Some children in this study self-initiated these non-pharmacological strategies, although many needed their parents or nurses to arrange these interventions for them. Providing each child the opportunity to choose non-pharmacological strategies are important measures that help children feel a sense of control and supports them as active agents in decision making and managing their pain. (Nilsson, Hallqvist, Sidenvall, & Enskar, 2011).

Together with the non-pharmacological strategies, children described medications and physical care measures as important treatments undertaken by nurses to help with their pain. Whilst some treatments contributed to their pain, children expressed their understanding that these were both necessary and helpful. As well as accurately reporting their pain experiences, this highlights children's ability to understand both positive and negative aspects of pain management. This degree of understanding supports the notion that children should be involved in all aspects of their pain management (Nilsson et al., 2011). Furthermore, when children are involved as active agents in their care, they are better able to cope with the situation (Coyne, 2008).

The strategies that children identified as effective in helping their pain were intrinsically linked to their need to feel secure in the presence of their primary caregiver. Establishing a trusting relationship between the nurse and child also contributed to the children's sense of security. The view that children are more able to build trust with nurses who take time to listen, provide honest and understandable information, and who demonstrate

clinical competence (Crandall, Kools, Miaskowski, & Savedra, 2007; Kortessluoma, Nikkonen, & Serlo, 2008) is supported by children's reports that nurses help by spending time playing games with children and explaining procedures before undertaking clinical tasks. On the other hand, children are less likely to trust nurses who they perceive as lacking skills or a gentle bedside manner (Pope, Tallon, McConigley, et al., 2017). This emphasizes the psycho-physiological dimensions of protection, support and caring whereby children need to feel secure (Holmes, 2014), particularly when they have pain. Further, fostering a climate where children feel secure is important as it can help them to share their experiences more openly with others (Gardner & Randall, 2012; Huang et al., 2016). This highlights the importance of providing nursing care that focuses on the child and is inclusive of the primary caregiver, in keeping with the philosophy of family centered care (Shields, 2010).

## **6.6 Conclusion**

This study is the first to use the DWT technique with children to explore their perceptions of pain and pain management within an Australian ED. Through this approach it was found that children were capable of giving detailed accounts of their pain experiences. Children were able to identify positive and negative aspects of care that helped with their pain. These findings support that children are in tune with the visual, auditory, and sensory dimensions of their pain experiences. However, none of this was possible without a sense of security. This security extended beyond the primary caregiver to include developing rapport and trust with nurses and a connection with aspects of their physical environment. Non-pharmacological strategies by nurses were identified both in the experiences and expectations of children as actions that both helped with pain and fostered security. The children's feelings about taking their minds off their pain, resting their bodies, and understanding hospital things, emphasizes the importance of effectively incorporating non-pharmacological approaches into the care and the management of children in pain.

## **6.7 Study limitations and implications for future research**

Findings were limited to children aged four to eight years. Interviews with children were short in duration (4-17 minutes) which may be considered a limitation. However, prolonged engagement prior to interview as advocated by Lincoln and Guba (1986)



helped to establish rapport and enhance data quality. Furthermore, the questions were important to the consumers and healthcare professionals because they were formed in consultation with the stakeholder group. This study captured the views of children with mild to moderate pain. As the children needed to be able to communicate with the researcher, those who were non-English speaking were not captured. Engaging professional interpreters for this purpose was not possible within the scope of this study. The medical needs of the children took precedence over the study, therefore the views of children with severe acute pain were not included. The views of children with chronic pain were also not captured because of the range of complex psychosocial and behavioural responses associated with chronic pain in children which warrants separate examination. More research using engaging methods to explore children's experiences in other settings are warranted to expand on these findings. Future research could examine the role of children as collaborative partners with an emphasis on a multifaceted, psychosocial assessment and decision making particularly relating to non-pharmacological approaches to their pain management. In this study, drawing was an effective way for children to share their experiences. More research is required to determine if drawing and similar activities could be integrated into clinical practice as a way to assess pain and engage children in decision making.

Effective pain management is one of the most important responsibilities of pediatric healthcare professionals. Nurses need to enable children to provide detailed accounts of their pain and pain needs that extends beyond the physical experience to include sensory and emotional aspects of their pain. These findings highlight the importance of nurses building rapport and trust while also protecting children from distressing visual and audio stimuli in the ED setting. Because children can appreciate the need for procedures that can be painful in managing their pain, it is important that the information offered to children is honest and understandable. Greater attention to the therapeutic use of non-pharmacological strategies is needed by supporting children to engage in activities that they enjoy to help take their minds off their pain. In addition to listening to primary caregivers, acknowledging that children are capable in being actively involved in their pain management and enabling them to have a voice in decision making is key to effective pain management for children.

## **Conflict of interest**

The authors report no actual or potential conflicts of interest.

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### *Chapter Summary*

The DWT technique allowed children to express their pain related experiences in a non-intimidating and inclusive manner and was an effective way to gain insight into their pain and pain needs while in the ED. Findings from thematic analysis were reported and a conceptual framework was developed to represent the named themes and subthemes, and their relationship to each other. The conceptual framework was used to guide the presentation and discussion of findings. Results of the study showed that children need to feel secure when they have pain. Furthermore, children as young as four years old can describe their pain and should be included in decisions about their pain. The following chapter summarises the findings addressing each of the study objectives and offers implications for nursing practice and research.

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## Chapter 7 Implications and Conclusions

This thesis presents the first study to use the DWT technique to explore children's experience of pain within a paediatric ED. Using the DWT children were able to create pictures, write words and verbally express various dimensions of their pain experience which may have been difficult to articulate using language alone. The primary aim of this study was to explore children's perceptions of pain and pain management provided in the ED of a Western Australian tertiary paediatric hospital. Findings showed that security was essential to children's experiences and enabled children to share detailed accounts of their pain that included physical, emotional, and sensory dimensions. Children's pain management needs extended beyond the use of pharmaceuticals to include various non-pharmacological pain relieving strategies.

The specific objectives to meet this study's aim were to explore children's perceptions of:

1. their pain while in the ED
2. their pain management provided while in the ED
3. the role of the nurse in pain management.

In response to these objectives, findings from the thematic analysis were reported and informed the development of a conceptual framework which represented the named themes and subthemes, and their relationship to each other. The conceptual framework was used to guide the presentation and discussion of results (Chapter 6). The following chapter further explores the findings by addressing each of the study's objectives in light of the literature, particularly the SR.

Most results of the study were consistent with those of the SR and reinforced existing knowledge that pain in children is a multifaceted phenomenon incorporating physiological, sensory, cognitive, affective, spiritual and behavioural dimensions (World Health Organisation, 2012). Findings supported the view that children's pain experiences are also influenced by several factors including their sociocultural background, past experiences, memories and their perceived consequences of pain (Craig, 2015; Noel et al., 2017; Simons, 2015; Wen et al., 2013).

Children needed to feel secure when they had pain, and this was evident across all three of the study objectives. Findings from the study highlighted that establishing a sense of security influenced children's pain experiences in three ways; firstly, it was essential to allow children to share their experiences of pain openly; secondly, feeling secure enabled children to identify strategies that helped them when they had pain, and thirdly, feeling secure offered a form of comfort for children which helped to relieve their pain. These findings were consistent with findings from the SR.

Relational and environmental aspects were also found to contribute to the children feeling secure. The presence and nurturing actions of a primary caregiver helped foster a sense of security for children. These findings emphasise the influence of a strong attachment and affectional bond between a child and their primary caregiver in contributing to children feeling secure in a time of stress (Bowlby, 1969). The influence of the presence of primary caregivers was also evident in the SR which showed that children's pain and distress is exacerbated in the absence of a primary caregiver. In addition to primary caregivers, the children emphasised how the establishment of a trusting relationship between the nurse and child helped to support a sense of security for children. This finding is in line with existing literature which describes trust as an essential element to the child-nurse relationship, and indeed partnership building (Caldwell, 2015; Roberts, Fenton, & Barnard, 2015). In addition, these findings are in keeping with biopsychosocial model of pain assessment (Varni, 1995) which emphasises the importance of having an awareness of the psychological and social factors that influence a child's pain experience.

Aspects of the child's environment were also found to be essential to the children's sense of security. Results of the SR and the study emphasised the importance of supporting an environment that is both familiar and comfortable for children. Having familiar objects, such as a toy, ensuring privacy, and providing comfort measures such as a blanket, helped foster a secure environment for children. These findings are in keeping with those of another SR examining children's experiences of post-operative pain where the importance of a familiar and comfortable environment was identified (Wen et al., 2013). Further to this, another study has shown that creating a familiar and comfortable environment for children in hospital positively impacts their experience and health outcomes (Hamdan, Alshammry, Tamani, Peethambaran, & Alharbi, 2016). These findings highlight aspects emphasised in the PAST model (Schiavenato &

Craig, 2010) which describes how the child's physical and social environment can foster a sense of security and positively influence their pain experiences (Craig, 2015; Schiavenato & Craig, 2010).

### **7.1 Objective 1: Children's Perceptions of Their Pain While in ED**

Findings from the study showed that children as young as four years of age were able to pinpoint the source of their pain, and use words to express sensory, affective and cognitive aspects of their pain. Children also used metaphors to describe the intensity, severity and quality of their pain. These findings align with existing evidence exploring children's views of pain (Wen et al., 2013; Woragidpoonpol et al., 2013) and support the recommended practice to use children's self-reports of pain as a reliable method in their pain management (Association of Paediatric Anaesthetists, 2012).

The way children expressed their pain reflected their developmental age. Younger children tended to describe their pain in definitive terms as expressed by one participant, Thomas, age five years who said, '*I felt like my leg was broken*'. Older children were able to relate their pain more abstractly to their experiences of the world. This allowed them to communicate their pain experience by using unrelated examples based on their understanding of phenomena. For example, for Spencer, aged eight years, his pain felt like he '*ran into a TNT*'. These findings support existing evidence which shows that children begin to develop pain related vocabulary from as young as 18 months of age and as their linguist and cognitive skills develop, their expressions of pain become increasingly more sophisticated (Drendel et al., 2011; Esteve & Marquina-Aponte, 2012; Franck et al., 2010).

Alongside physical sensations, emotional dimensions of children's pain were evident in findings from the SR and the study where emotions such as fear, anxiety and apprehension were commonly featured in children's descriptions of their pain. These emotions seemed to intensify and worsen children's pain, a view supported by Chieng et al. (2012), in their SR, who found that negative emotions, such as anxiety, are often more unpleasant for children than physical pain itself. Findings from the study showed that children can describe positive emotions related to their pain, such as feeling happy, yet these feelings were associated with children having completed medical treatment, leaving the hospital, or when their pain was gone. This finding emphasises factors

described in the “CARES” model of pain assessment (Twycross et al., 2015) which draws attention to the importance of a comprehensive, biopsychosocial approach in the assessment of children’s pain which is inclusive of a child’s emotional responses to pain.

Children’s perceived consequences of their pain were also found to contribute to their emotions. Findings from both the SR and the study showed that being in pain meant that children were not able to participate in activities they enjoyed, such as playing with friends. Similarly, findings from an earlier qualitative study exploring the pain experiences of children in hospital (aged 2-7 years), showed for these children, pain limited their ability to engage in their usual daily activities (Woodgate & Kristjanson, 1996).

In addition to the emotional dimensions of pain, aspects of the visual sensory processes of pain were reflected in the results of the study, whereby visual cues, such as the site of blood exacerbated children’s pain experience. This finding supports the view that external sensory processes such as sights influence pain perception (Benuzzi et al., 2008; Price, 2000) and can increase anxiety (Tse, Ng, Chung, & Wong, 2002).

These results demonstrate that children’s experiences of pain extend beyond physical dimensions to include sensory qualities, as well as affective and cognitive dimensions, a notion in keeping with both the biopsychosocial model of pain assessment (Varni, 1995) and the PAST model (Schiavenato & Craig, 2010). Furthermore, children as young as four years old are able to articulate these dimensions of pain to provide detailed insights into their experience.

## **7.2 Objective 2: Children’s Perceptions of Pain Management in ED**

In addition to describing sensory and affective dimensions of pain, children were also aware of both positive and negative aspects of their pain management. A new finding from the study showed that children as young as four years of age understood that while some treatments contributed to their pain, these were necessary procedures undertaken to help when they had pain. This level of insight supports the view that children rely on the provision of honest and understandable information related to their treatment (Nilsson et al., 2011b), even when treatment is likely to cause them pain.

Findings from the study support those from the SR and widely documented evidence identifying the effectiveness of non-pharmacological strategies in the treatment of

children's pain (Mu et al., 2009; Simons, 2015; Wen et al., 2013; Woragidpoonpol et al., 2013). Children could identify a range of cognitive, sensory and environmental strategies that help when they have pain. Cognitive activities such as drawing, watching television, playing games, and going outside helped children take their mind off their pain. While rubbing where it hurts, positioning and applying heat and cold packs were among sensory strategies that children found helpful. There was little difference between the cognitive and sensory strategies used by children in the study to those in the SR and other SRs examining non-pharmacological management of children's pain (Pillai Riddell et al., 2015; Wen et al., 2013; Woragidpoonpol et al., 2013). Further, these findings support the capacity of young children to be involved as active agents in their pain management, a view consistent with other studies examining the management of children's pain (Kortessluoma et al., 2008; Twycross & Finley, 2013).

The value of resting featured in the findings of the study, where children expressed a desire to rest their bodies and lie down as a way to escape from their pain. Interviews with Singaporean children (6-12 years old) revealed similar results (Sng et al., 2013), where children favoured resting and sleeping as methods to help with their post-operative pain.

While children were capable of initiating many non-pharmacological strategies, findings of both the SR and the study showed that children also regarded their primary caregivers and healthcare professionals as important sources of help. In addition, children depended on their primary caregivers to initiate non-pharmacological strategies such as drawing or using a hot pack. Similarly, the importance of supporting parents to initiate various non-pharmacological measures to help children when they have pain was emphasised in a SR by Hoon et al. (2011) that examined parental involvement in children's post-operative pain. Alongside initiating non-pharmacological strategies, results from both the SR and the study showed that children relied on primary caregivers to be their advocates, to help with their daily tasks, and provide information related to their treatment. Similar findings have been reported in SRs examining children's post-operative pain (Hoon et al., 2011; Woragidpoonpol et al., 2013), and draws attention to the importance of encouraging, supporting and facilitating primary caregivers' involvement in their children's care.

As well as looking to their primary caregivers, children identified healthcare professionals as important to help manage their pain. In both the SR and the study, nurses were the most commonly identified healthcare professional in the provision of care. As with their primary caregivers, children depended on nurses to facilitate non-pharmacological strategies and help with their everyday needs. Further to this, they relied on nurses to provide honest and understandable information related to their care. This openness with children has been shown to lower distress levels (Sng et al., 2013) and contributes to establishing trust between the nurse and child (Caldwell, 2015; Roberts et al., 2015).

In addition to non-pharmacological strategies, medications were identified by children as helpful in treating their pain in both the SR and the study. Children in the study were able to name a range of pain relief medications (i.e. paracetamol). They also reported the pain relief medication was not always effective in alleviating their pain. This draws attention to the benefits of combining non-pharmacological and pharmacological therapies, in treating children's pain, a recommendation which conforms to best practice guidelines (Association of Paediatric Anaesthetists, 2012).

### **7.3 Objective 3: Role of the Nurse**

Of all healthcare professionals, children in the study identified nurses as the most involved in managing their pain in the ED. A finding that emerged from the SR was that children can articulate characteristics of nurses that they perceived helpful and unhelpful to pain management. Nurses who children perceived as dismissive, intimidating and lacking clinical skills were considered unhelpful. Children were less likely to build trust with these nurses. These findings were not reflected in the study, which may be attributed to the age of participants; where the SR captured views of older children (4-18 years old), who were not captured in the study (4-8 years). Further research is needed to explore this in more depth.

The nurse's role in facilitating pharmacological and non-pharmacological pain-relieving strategies was shown in findings from both the SR and the study. Building trust with children was essential to allow effective provision of pharmacological and non-pharmacological nursing strategies to occur. Furthermore, evidence has shown that when children develop trust with nurses, they report more positive experiences



associated with their care (Caldwell, 2015; Nilsson, List, & Willman, 2011a). Findings from both the SR and the study support the view that children build trust more easily with nurses who demonstrate clinical competence and who take time to listen to children (Caldwell, 2015; Wen et al., 2013). Also, essential to trust and effective pain management is the provision of honest and understandable information by the nurse (Roberts et al., 2015).

As well as the provision of effective pharmacological and non-pharmacological strategies, children depend on nurses to support and maintain an environment free from potentially distressing materials common in hospital settings, such as blood or clinical instruments. As outlined earlier, findings from the study showed that these noxious visual cues exacerbated children's pain. This also contributes to supporting an environment where children feel safe. This finding aligns with existing evidence which has shown that potentially distressing visual cues can impact how the brain processes pain, intensifying the pain experience (Benuzzi et al., 2008; Ogino et al., 2007).

As highlighted previously, pain relief medication helped children when they had pain. Findings from the study emphasised that children depended on nurses to provide timely pain relief medication and this was linked to a nurse's clinical competence. This finding was also reflected in findings of the SR.

#### **7.4 Strengths and Limitations of the Study**

This was the first study to use the DWT with children to explore their perceptions of pain and pain management within a paediatric ED. The DWT offered a means to motivate communication to capture children's experiences of pain. Using this approach, it was found that children are capable of describing a range of sensory and emotional characteristics of their pain and identify a number of strategies that help when they are in pain.

Stakeholder engagement was an essential feature of this study to inform the research objectives and to ensure that the study was meaningful to children, families and staff in the ED. Despite these strengths, there are some limitations to the study.

First, the inclusion criteria for the study meant that only the views of children with mild to moderate acute pain were captured. Children with severe acute pain and those living with chronic pain were not included. Secondly, the study only captured the views of

children who could speak and understand English. The data from the study could have been enriched if children from non-English speaking backgrounds had been included.

Finally, the study was carried out in one paediatric setting. Caution is required when translating the findings to other settings. However, the thick, rich description of the setting enhances the transferability of findings to English speaking children who present to a paediatric ED in pain. While the interviews with children were short in duration (4-17 minutes), prolonged engagement ensured that the transcripts focused exclusively on the children's pain experiences.

## **7.5 Implications for Clinical Practice**

A sense of security should be fostered for all children receiving treatment for their pain. The nurse's role in supporting a sense of security is diverse. Given that a secure, nurturing and responsive attachment between a child and their primary caregiver supports positive psychological outcomes for children in pain (Barone et al., 2016), nurses need to welcome and encourage all opportunities for primary caregivers to be involved in their child's care.

The establishment of a trusting relationship between the nurse and child is imperative and depends on nurses demonstrating an attentive, nurturing bedside manner, as well as providing children with honest and understandable information about their care. Given that children can appreciate the need for procedures that can be painful this openness with children is likely to enhance trust.

In addition to these relational aspects, nurses need to pay attention to a child's physical environment. Offering privacy, such as closing the curtains, and providing comfort measures such as helping children to rest in bed, support an environment where children feel safe. Having familiar items, such as a toy, or other personal belongings is also important. Moreover, nurses need to find ways to minimise a child's exposure to visual cues associated with pain, such as the sight of blood. This is particularly relevant in clinical areas where healthcare is undertaken with urgency, such as an ED, or in settings that are not exclusively tailored to the care of children.

Children need to be recognised as active agents in their pain assessment. A comprehensive approach to pain assessment which appreciates the complex and dynamic social transaction between the patient and healthcare professional is essential

to effective pain management (Schiavenato & Craig, 2010; Voepel-Lewis et al., 2012). Pain assessment should begin by undertaking a detailed health history to record information related to a child's development, their sociocultural background, as well as previous pain experiences and needs. Each of these factors influence the way a child behaves when they have pain, how they express their pain, and what they might need to comfort them when they have pain. Undertaking a physical examination and obtaining pain scores using validated pain assessment tools is also important.

In addition, nurses need to listen to children and support children to express their pain in ways that extend beyond physical dimension to include how they feel about their pain. Taking time to talk with children and capture their subjective pain experience is important to better understand their pain (Voepel-Lewis et al., 2012). Identifying pain words that are familiar to the child, and enquiring through questions such as; "Can you tell me what your pain feels like?", "How does your pain make you feel?", "Is there anything else you would like to tell me about how you feel?" may help to capture features of pain beyond physical dimensions such as sensory qualities as well as affective and cognitive dimensions of pain (Twycross et al., 2015).

Nurses need to work collaboratively with children and families to effectively incorporate non-pharmacological strategies as part of a comprehensive, multi-modal approach to pain management. Involving children in decisions related to the pharmacological and non-pharmacological strategies is important to partnership in care. Asking questions such as "What helped you feel better last time?" and "What will make you feel better now?" will help to incorporate strategies that are appropriate and of interest to the child.

## **7.6 Implications for Research**

Opportunities for future research have been identified. Given that children rely on others such as nurses and primary caregivers in managing their pain, it could be useful to explore the perspectives of each of these groups to examine potential ways to enhance assessment and management of children's pain. Together these insights may offer new knowledge about approaches to care for children in pain.

In keeping with findings from this study, collaboration with children as stakeholders, including those as young as four, will ensure their capacity as active agents in their

care is acknowledged. A further research opportunity could see the formation of a stakeholder group, including children, to design a comprehensive pain assessment instrument that incorporates other important dimensions of pain such as sensory, cognitive and affective features, as well as a section for children to be included in decision making related to their pain relief. Such a tool could then be introduced into practice and evaluated for feasibility and the effect on pain management practices.

In this study drawing was an effective way to gain insight into children's experiences. This invites consideration for the juxtaposition DWT holds across both research and practice. Further research is needed to explore the possibility of incorporating the DWT technique in pain assessment.

## **7.7 Conclusion**

An exploration of children's experiences of pain using a qualitative method with an inductive approach showed that children as young as four years were capable of giving detailed accounts of their pain experiences. Children's descriptions of their pain extended beyond physical sensations, and included sensory, affective and cognitive dimensions. Children were capable of identifying aspects of care that were helpful and unhelpful to their pain. However, none of this was possible without a sense of security. Children's sense of security was dependent on the presence of a supporting parent and nurturing actions of primary caregivers and developing rapport and trust with nurses. Aspects of their physical environment also contributed to a child's sense of security. Alongside pharmacological strategies, the effectiveness of non-pharmacological measures were identified by children as important strategies to manage their mild to moderate pain. Taking the time to listen to children and their primary caregivers in order to provide honest and understandable information related to their care is essential. Children should be encouraged and supported as active agents in all aspects of their pain management, including enabling children to have a voice in decision making about interventional strategies. These measures will help to improve pain management for children and contribute to optimal health outcomes for children and their families.

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### **Copyright Acknowledgement**

*Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.*

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## APPENDICES

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## Appendix A Search Strategy

Search on 11/12/2015

CINAHL		
Concept	Searches	Keywords
Concept 1	S1	(MH "Pain") OR Tx "pain"
	S2	Tx Acute pain
	S3	<i>Combine S1 OR S2</i>
Concept 2	S4	(MH "Adolescence") OR (MH "Child")
	S5	Tx child*
	S6	Tx "pediatric"
	S7	Tx "paediatric"
	S8	<i>Combine S4 OR S5 OR S6 OR S7</i>
Concept 3	S9	(MH "Perception") OR Tx"perception"
	S10	(MH "Life Experiences") OR Tx "experience"
	S11	(MH "Qualitative Studies")
	S12	Tx Qualitative
	S13	<i>Combine S9 OR S10 OR S11 OR S12</i>
Exclusion	S14	(MH "Postoperative Pain")
Combined search	S17	S3 AND S8 AND S13 NOT S14

### Legend

MH = CINAHL Exact Subject Heading TX = Keyword Limiters:

\* Added to the end of the root word to find the root word plus all the words made by adding letters

*Limiters:*

Published Date: 2000-2016; English Language; age groups: Child, Preschool: 2-5 years, Child: 6-12 years,

Adolescent: 13-18 years

## Search on 13/12/2015

Medline		
Concept	Searches	Keywords
Concept 1	S1	child*.mp. or Child/
	S2	Adolescent.mp. or Adolescent/
	S3	p?ediatric*
	S4	<i>Combined S1 OR S2 OR S3</i>
Concept 2	S5	“experience”*.m_titl.
	S6	perception*.mp. or Perception/
	S7	“meaning”*.m_titl.
	S8	“qualitative”*.m_titl.
	S9	<i>Combine S5 OR S6 OR S7 OR S8</i>
Concept 3	S10	pain.mp. or Acute Pain/ or Pain/
Exclusion	S11	Pain, Postoperative/
Combined search	S15	S4 AND S9 AND S10 NOT S11

### Legend

/ = Medical Subject Headings MeSH

mp. = multipurpose (search looks in the Title, Original Title, Abstract, Subject Heading, Name of Substance, and Registry Word fields)

\* Added to the end of the root word to find the root word plus all the words made by adding letters

### Limiters:

English language and yr="2000 -Current" and ("preschool child (2 to 5 years)" or "child (6 to 12 years)" or "adolescent (13 to 18 years)")

## Search on 20/12/2015

Scopus		
Concept	Searches	Keywords
Concept 1	S1	Pain (TITLE-ABSTRACT-KEYWORD)
Concept 2	S2	Pediatric* (TITLE-ABSTRACT-KEYWORD)
	S3	Child* (TITLE-ABSTRACT-KEYWORD)
	S4	Combine S2 OR S3
Concept 3	S5	Perception (TITLE-ABSTRACT-KEYWORD)
	S6	Qualitative (TITLE-ABSTRACT-KEYWORD)
	S7	Combine S5 OR S6
Combined search	S11	S1 AND S4 AND S7

### Legend

\* Added to the end of the root word to find the root word plus all the words made by adding letters

### Limiters:

Publication data >1999, English

## Search on 21/12/2015

ScienceDirect		
Concept	Searches	Keywords
Concept 1	S1	TITLE-ABS-KEY("perception")
	S2	TITLE-ABS-KEY("experience")
	S3	TITLE-ABS-KEY("qualitative")
	S4	Combine S1 OR S2 OR S3
Concept 2	S5	TITLE-ABS-KEY("child")
	S6	TITLE-ABS-KEY("pediatric")
	S7	TITLE-ABS-KEY("adolescen")
	S8	Combine S5 OR S6 OR S7
Concept 3	S9	TITLE-ABS-KEY("pain")
	S10	TITLE-ABS-KEY("acute pain")
	S11	Combine S9 OR S10
Exclusion	S12	TITLE-ABS-KEY("operat pain")
Combined search	S15	S4 AND S8 AND S11 NOT S12

### Legend

The search TITLE-ABS-KEY returns documents where the terms appear in the title, keywords, or abstract.

\* Added to the end of the root word to find the root word plus all the words made by adding letters to the end of it.

### Limiters:

Publication date > 1999

## Search on 22/12/2015

PsycINFO		
Concept	Searches	Keywords
Concept 1	S1	exp Pain Perception/
	S2	experience* adj3 pain.mp.
	S3	<i>Combine S1 OR S2</i>
Concept 2	S4	child*.mp
	S5	adolesc*.mp
	S6	P?ediatric
	S7	<i>Combine S4 OR S5 OR S6</i>
Concept 3	S8	exp Qualitative Research/ or qualitative.mp.
Exclusion	S9	exp Chronic Pain/
Combined search	S13	<i>Combine S3 AND S7 AND S8 NOT S9</i>

### Legend

/ = Medical Subject Headings MeSH

mp. = multipurpose (search looks in the Title, Original Title, Abstract, Subject Heading, Name of Substance, and Registry Word fields)

\* Added to the end of the root word to find the root word plus all the words made by adding letters

exp= indicates the index term was exploded

*Limiters:*

Publication date 2000-2016, English

## Search on 28/12/2015

ProQuest		
Concept	Searches	Keywords
Concept 1	S1	“PAIN”
Concept 2	S2	“CHILDREN AND YOUTH”
	S3	“CHILDREN YOUTH”
	S4	“CHILD”*
	S5	<i>Combine S2 OR S3 OR S4</i>
Combined search	S6	S1 AND S5

### Legend

\* Added to the end or start of the root word to find the root word plus all the words made by adding letters to the end of it or start of it.

*Limiters:*

Publication date: 2000 – 2016, English

## Search on 24/12/2015

Embase		
Concept	Searches	Keywords
Concept 1	S1	Pain perception.mp.
	S2	(experience adj3 pain).tw.
	S3	<i>Combine S1 OR S2</i>
Concept 2	S4	child/
	S5	adolescent/
	S5	<i>Combine S4 OR S5</i>
Exclusion	S6	postoperative pain/
Combined search	S7	S3 AND S5 NOT S6

### Legend

/ = Medical Subject Headings MeSH

mp. = multipurpose (search looks in the Title, Original Title, Abstract, Subject Heading, Name of Substance, and Registry Word fields)

adj3 = two terms where they appear adjacent to one another (in this case within 3 words)

tw= textwords in title/abstract

*Limiters:*

English language and yearr="2000 -Current"

## Search on 27/12/2015

Web of Science		
Concept	Searches	Keywords
Concept 1	S1	Child*
	S2	P?ediatric
	S3	<i>Combine S1 OR S2</i>
Concept 2	S4	Pain
	S5	Acute Pain
	S6	<i>Combine S4 OR S5</i>
Concept 3	S7	Perception
	S8	Qualitative
	S9	Pain near/3 experience
	S10	<i>Combine S7 OR S8 OR S9</i>
Combined search	S14	S3 AND S6 AND S10

### Legend

\* Added to the end or start of the route word to find the root word plus all the words made by adding letters to the end of it or start of it.

Pain near/3 experience = two terms where they appear adjacent to one another (in this case within 3 words)

*Limiters:*

English

### Search on 23/12/2015 @1400hrs

MedNar		
Concept	Searches	Keywords
Concept 1	S1	Experience
	S2	Perception
	S3	Qualitative
	S4	<i>Combine S1 OR S2 OR S3</i>
Concept 2	S5	Pain
	S6	Acute Pain
	S7	<i>Combine S5 OR S6</i>
Concept 3	S8	Child*
	S9	Pediatric
	S10	<i>Combine S8 OR S9</i>
Combined search	S11	<i>Combine S4 AND S7 AND S10</i>

#### Legend

\* Added to the end or start of the root word to find the root word plus all the words made by adding letters to the end of it or start of it.

### Search on 29/12/2015

ProQuest Dissertations and Thesis Global		
Concept	Searches	Keywords
Concept 1	S1	“PAIN”
Concept 2	S2	“CHILDREN AND YOUTH”
	S3	“CHILDREN YOUTH”
	S4	“CHILD”*
	S5	<i>Combine S2 OR S3 OR S4</i>
Combined search	S6	<i>Combine S1 AND S5</i>

#### Legend

\* Added to the end or start of the root word to find the root word plus all the words made by adding letters to the end of it or start of it.

*Limiters:*

Publication date: 2000 – 2016, English

## Search on 30/12/2014 @ 1200hrs

Google Scholar		
Concept	Searches	Keywords
Concept 1	S1	Pain
Concept 2	S2	Experience
	S3	Perception
	S4	Qualitative
	S5	<i>Combine S2 OR S3 OR S4</i>
Concept 3	S6	Child
	S7	Children
	S8	Paediatric
	S9	Pediatric
	S10	<i>Combine S6 OR S7 OR S8 OR S9</i>
Exclusion	S11	Chronic pain
Combined search	S17	<i>Combine S1 AND S5 AND S10 NOT S11</i>

### Legend

#### Limiters:

Publication date 2000-2016

Note: Key terms searched in title. 'Find similar' tab utilized for further searching

## Appendix B Appraisal Instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year ..... Record Number .....

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:  Include  Exclude  Seek further info.

Comments (Including reason for exclusion)

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## Appendix C Data Extraction Instrument

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year .....

Journal ..... Record Number .....

**Study Description**

Methodology  
\_\_\_\_\_  
\_\_\_\_\_

Method  
\_\_\_\_\_  
\_\_\_\_\_

Phenomena of interest  
\_\_\_\_\_  
\_\_\_\_\_

Setting  
\_\_\_\_\_  
\_\_\_\_\_

Geographical  
\_\_\_\_\_  
\_\_\_\_\_

Cultural  
\_\_\_\_\_  
\_\_\_\_\_

Participants  
\_\_\_\_\_  
\_\_\_\_\_

Data analysis  
\_\_\_\_\_  
\_\_\_\_\_

Authors Conclusions  
\_\_\_\_\_  
\_\_\_\_\_

Comments  
\_\_\_\_\_  
\_\_\_\_\_

Complete                      Yes                       No

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes

No

## Appendix D Excluded Studies

### Studies eliminated based on not fulfilling the inclusion criteria

Björkman, B., Golsäter, M., & Enskär, K. (2014). Children's anxiety, pain, and distress related to the perception of care while undergoing an acute radiographic examination. *Journal of Radiology Nursing*, 33(2), 69-78. doi: 10.1016/j.jradnu.2013.12.003

**Reason for exclusion:** *The qualitative findings of this study did not meet the inclusion criteria relating to the outcomes of interest.*

Björkman, B., Almqvist, L., Sigstedt, B., & Enskär, K. (2012). Children's experience of going through an acute radiographic examination. *Radiography*, 18(2), 84-89. doi: 10.1016/j.radi.2011.10.003

**Reason for exclusion:** *This study aimed to examine children's experiences undergoing a radiographic examination for a suspected fracture, rather than children's experiences of pain. The aim of this study did not meet the inclusion criteria.*

Borghi, C. A., Rossato, L. M., Damiao, E. B. C., Guedes, D. M. B., da Silva, E. M. R., Barbosa, S. M. D., & Polastrini, R. T. (2014). Living with pain: the experience of children and adolescents in palliative care. *Revista da Escola de Enfermagem da USP*, 48, 67-73. doi: 10.1590/s0080-623420140000600010

**Reason for exclusion:** *The participants included children with chronic diseases receiving pain treatment and had no distinction in the results between patients with chronic or acute pain.*

Carnevale, F. A., & Gaudreault, J. e. (2013). The experience of critically ill children: A phenomenological study of discomfort and comfort. *Dynamics*, 24(1), 19-2

**Reason for exclusion:** *The phenomenon of interest did not meet inclusion criteria, this study sought to examine children's experience of critical illness rather than acute pain specifically.*

Crandall, M., Kools, S., Miaskowski, C., & Savedra, M. (2007). Adolescents' pain experiences following acute blunt traumatic injury: Struggle for internal control. *Journal for Specialists in Pediatric Nursing*, 12(4), 224-237. doi: 10.1111/j.1744-6155.2007.00118.x

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria. This study sought to explore conceptual relationships and resulted in the generation of an initial substantive theory. Data presented in this study had already been used in one of the final articles selected for this systematic review.*

Franck, L., Sheikh, A., & Oulton, K. (2008). What helps when it hurts: children's views on pain relief. *Child: Care, Health and Development*, 34(4), 430-438. doi: 10.1111/j.1365-2214.2008.00812.x

**Reason for exclusion:** *The participants targeted all children who had visited the hospital, including inpatients, outpatients and visitors. The children who were not inpatients did not have acute pain. It was not specific to children who had acute pain in a healthcare facility.*

Harrison, D., Joly, C., Chretien, C., Cochrane, S., Ellis, J., Lamontagne, C., & Vaillancourt, R. (2014). Pain prevalence in a pediatric hospital: Raising awareness during Pain Awareness Week. *Pain Research & Management*, 19(1), e24-e30.

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria, this study sought to describe the prevalence of pain, pain assessment and pain management practices at a tertiary pediatric hospital, rather than pain experiences of children. No qualitative findings reported.*

Jongudomkarn, D., Aungsupakorn, N., & Camfield, L. (2006). The meanings of pain: A qualitative study of the perspectives of children living with pain in north-eastern Thailand. *Nursing and Health Sciences*, 8(3), 156-163. doi: 10.1111/j.1442-2018.2006.00273.x

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria. Participants recruited did not meet the inclusion criteria. One group of participants were recruited in a community setting and the other were children with chronic conditions. The latter group shared experiences related to chronic pain.*

Kin-Fong Cheng, K. (2009). Oral mucositis: A phenomenological study of pediatric patients' and their parents' perspectives and experiences. *Supportive Care in Cancer*, 17(7), 829-837. doi: 10.1007/s00520-009-0618-2

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria and provide reason why as you have above.*

Kortesluoma, R., Punamäki, R., & Nikkonen, M. (2008). Hospitalized children drawing their pain: the contents and cognitive and emotional characteristics of pain drawings. *Journal of Child Health Care, 12*, (4),284-300. doi: 10.1177/1367493508096204

**Reason for exclusion:** *The aim of this study was to examine how children's illness and hospitalization are associated with the contents and cognitive and emotional characteristics of their drawings, rather than the children's experiences of acute pain. Study did not meet inclusion criteria.*

Kortesluoma, R., & Nikkonen, M. (2004). 'I had this Horrible Pain': The Sources and Causes of Pain Experiences in 4- to 11-Year-Old Hospitalized Children. *Journal of Child Health Care, 8*(3), 210-231. doi: 10.1177/1367493504045822

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria. Data presented in this study had already been used in one of the final articles selected for this systematic review.*

Lindeke, L., Nakai, M., & Johnson, L. (2006). Capturing children's voices for quality improvement. *MCN The American Journal of Maternal/Child Nursing, 31*(5), 290-297.

**Reason for exclusion:** *The phenomenon of interest outlined in the inclusion criteria was not met, the children's perceptions of their inpatient healthcare was explored rather than acute pain specifically.*

Ljungman, G., Gordh, T., Sorensen, S., & Kreuger, A. (2000). Pain variations during cancer treatment in children: A descriptive survey. *Pediatric Hematology and Oncology, 17*(3), 211-221. doi: 10.1080/088800100276389

**Reason for exclusion:** *The study interviewed the parents rather than the children thus not meeting the criteria.*

Macartney, G., Stacey, D., Harrison, M. B., & VanDenKerkhof, E. (2014). Symptoms, coping, and quality of life in pediatric brain tumor survivors: A qualitative study. *Oncology Nursing Forum, 41*(4), 390-398. doi: 10.1188/14.ONF.390-398

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria, the participants had not presented with acute pain.*

Pederson, C., Parran, L., & Harbaugh, B. (2000). Children's perceptions of pain during 3 weeks of bone marrow transplant experience. *Journal of Pediatric Oncology Nursing, 17*(1), 22-32.

**Reason for exclusion:** *The phenomenon of interest did not meet the inclusion criteria.*

Romsing, J., Skovgaard, C. D., Friis, S. M., & Henneberg, S. W. (2014). Procedure-related pain in children in a Danish University Hospital. *A qualitative study. Pediatric Anesthesia, 24*(6), 602-607. doi: 10.1111/pan.12402

**Reason for exclusion:** *The methodology used to collect data did not meet the inclusion criteria. No qualitative themes were generated from the data analysis.*

### **Studies that did not meet quality assessment**

Kortesluoma, R., & Nikkonen, M. (2006). 'The most disgusting ever': Children's pain descriptions and views of the purpose of pain. *Journal of Child Health Care, 10*(3), 213-227. doi: 10.1177/1367493506066482

**Reason for exclusion:** *The study did not meet the standards for methodological quality of the JBI QARI Appraisal Checklist for Interpretive and Critical Research. There was no statement locating the researcher culturally or theoretically (criterion 6), nor was the influence of the researcher on the research (or vice-versa) addressed (criterion 7). There was also no evidence of ethical approval by an appropriate body (criterion 9). The congruity between the research methodology and the representation and analysis of data (criterion 4), and the interpretation of results (criterion 5) was unclear. It was also unclear whether the conclusions drawn in the report flowed from the analysis and interpretation of the data (criterion 10).*

## Appendix E Characteristics of Included Studies

Authors/Year/ Country	Aims/Purpose	Sample	Design and Methods	Setting	Findings
Cheng et. al  2003 Taiwan	To understand how Taiwanese children describe their pain experiences. The research question for the inquiry asked how hospitalized children verbally describe their experiences of pain.	90 children, aged 5-14 years, hospitalized, who had experienced acute pain from illness or needle related pain.	A qualitative descriptive design. Semi-structured interviews were used including open-ended and closed-ended questions.	Five hospitals in southern Taiwan.	Seven themes; definition of pain, quality of pain, previous pain experiences, pain expectation, pain acceptance, causes of pain and meaning of pain. The results of this study revealed few differences in the experiences and meanings of pain. Most results are consistent with the studies done in the US. Differences are minor, including the interpretation of children's crying and how Taiwanese parents talk with their children about pain.
Crandall, M, Kools, S, Savedra, M  2002 United States of America	To describe the subjective pain experience of adolescents after a blunt traumatic injury (BTI).	13 adolescents, aged 11-17 years who were hospitalized following experiencing a BTI	The study employed a descriptive exploratory qualitative design. Interviews with open ended questions were used to collect data. Data were also collected using the Adolescent Pediatric Pain Tool (APPT), the Temporal Dot Matrix, and review of health records.	West coast university hospital designated as a pediatric adolescent trauma center	Five themes were developed; injury characteristics, pain descriptions recalled according to context, actions that adolescents recalled using to manage pain, present pain perceptions and unrelieved pain consequences. Findings demonstrate that unrelieved pain continues to be a problem for adolescents experiencing acute BTI. Clinicians need to improve their knowledge, attitudes, and behaviors regarding adolescent pain management.

<b>Authors/Year/ Country</b>	<b>Aims/Purpose</b>	<b>Sample</b>	<b>Design and Methods</b>	<b>Setting</b>	<b>Findings</b>
					Adolescents' identified pain relieving strategies that included providing analgesia, supportive family member and peer presence, and supportive clinicians' strategies
Kortesluoma, R, Nikkonen, M, Serlo, W  2008 Finland	To describe the interventions young children use themselves, and their expectations of other's help, when managing the pain experienced during hospitalization.	44 children, aged 8-11 years hospitalized who had experienced acute pain.	The study employed a qualitative descriptive design. Data was collected using open ended interview questions.	Four wards in a University Hospital in Finland.	Five themes were identified; Children's self-help strategies for pain, expectations of professional help, significant others as helpers, nothing can help and other generated sources of pain relief.  Developing a better and more informed understanding of the needs and expectations of the child in pain will help to target interventions that are effective and incorporate quality caring into practice.
Nilsson,S, Hallqvist, C, Sidenvall, B Enskär, K  2011 Sweden	To report the experiences of children of procedural pain when they underwent a trauma wound care session.	39 children,aged 5-10 years who suffered from wounds too advanced and too serious to be taken care of in a primary setting.	The study employed a qualitative descriptive design. Data was collected using open ended questions in conjunction with the procedure.	Pediatric day care unit in Sweden.	Four themes were identified: clinical competence, distraction, participation and security.  Children need to experience security and participation in wound care. When children feel that there is sufficient clinical competence in the wound care, they trust the nurse to carry out the wound dressing and can instead focus on the distraction that increases their positive outcomes.



## **Appendix F List of Study Findings from the Systematic Review**

### **Category 1.1: The physical and psychological dimensions of pain**

When sharing their pain stories, children verbally expressed both the physical sensations relating to their pain as well as the emotions they felt as a result of being in pain.

#### **Finding 1: Injury characteristics (Crandall et al., 2002) [C]**

##### *Illustration:*

“I was in a lot of pain and I was really kind of dizzy and I didn’t know what was going on. I just wanted to close my eyes and wake up from whatever dream I was in. I don’t know if I blacked out or if my hearing just went blank or whatever, but I just remember a little blitz of that ambulance Life Flight. I was really confused. All I knew was I had to lie there. My left side was hurting really bad. I think they like had me cut open too.” (p.106)

#### **Finding 2: Present pain descriptions (Crandall et al., 2002) [U]**

##### *Illustration:*

“They [staff] put IVs in and then they took them out, so that hurts... and inside of my cast on my leg, it itches and there’s like no way to get there. And I’m really hot because I have been having fevers. It makes me dizzy and sick. It’s [pain] uncontrollable, constant, continuous, awful, and shocking. I don’t know why, it just doesn’t stop.” (p.110)

#### **Finding 3: Meaning of pain (Cheng et al., 2003b) [U]**

##### *Illustration:*

“I felt something wrong. I am afraid I am going to die because I have lots of pain.” (p.246)

#### **Finding 4: Quality of pain (Cheng et al., 2003b) [U]**

##### *Illustration:*

“Just like I was bitten by red ants.” (p.244)

#### **Finding 5: Definition of pain (Cheng et al., 2003b) [U]**

##### *Illustration:*

“Pain means my body feels pain.” (p.244)

### **Finding 6: Causes of pain (Cheng et al., 2003b) [C]**

#### *Illustration:*

“Bacteria ran into my throat from my fingernails. Then, the bacteria jumped out. They needed to find a place that people would have a hard time finding”. (p.246)

### **Category 1.2 Previous knowledge and experiences influence the pain experience**

The shared pain experiences of children were influenced by a number of factors including their previous experiences, expectations of pain and sociocultural factors.

### **Finding 7: Previous pain experiences (Cheng et al., 2003b) [C]**

#### *Illustration:*

“One day, my parents took me to Mao-Lin for fun. I accidentally fell into the water and hit the rocks. When I fell in the water, it felt shiny and dark, I was extremely scared. I was afraid I wouldn’t see Mama anymore.” (p.245)

### **Finding 8: Pain expectation (Cheng et al., 2003b) [U]**

#### *Illustration:*

“Mama said I needed to have some tests. I asked Mama whether I would have pain, but Mama said no. I guess she lied to me”. (p.245)

### **Finding 9: Pain acceptance (Cheng et al., 2003b) [C]**

#### *Illustration:*

“If the child has pain that must from the child’s mind. Maybe the child would have a broken heart because he just looks different from other children.” (p.245)

### **Finding 10: Pain descriptions recalled according to context (Crandall et al., 2002) [C]**

#### *Illustration:*

“I had a really strange night and morning, you know, the withdrawal symptoms, I guess, or something. I had this severe hot flash, starting the evening just a couple of nights ago. I guess either the night before or last. Hot flashes constantly. Every 5 minutes I would wake up, really big hot flash, and then I’d be shivering cold and hot flash and then cold constantly the whole night. I had a really bad stomach ache and those two things were what really bothered me the most I think out of everything that’s gotten to me. That [morphine withdrawal] and the chest tube [removal]. When they took it [chest tube] out it hurt a lot. My eyes got wide open and I’m like whoa. I was worried about what they were doing. They [staff] could have given me a shot, anaesthesia, or something. I’m still hurting.” (p.108)

**Finding 11: Unrelieved pain consequences (Crandall et al., 2002) [C]**

*Illustration:*

“I had a bruised hip and I thought it was broken and when I walked it would just hurt so bad that it would just stop me from walking and I’d have to hold on to people, have people help me. I thought I’d never be able to walk or anything. I was gonna use crutches or something to get around and get teased at school. I have pains in it all the time.” (p.111)

**Category 2.1 Cognitive/behavioural and sensory/physical self-soothing actions children used to help manage their pain and anxiety**

Children of all ages called upon a variety of intuitively manifested self-soothing strategies to help relieve their pain.

**Finding 12: Children’s self-help strategies for pain (Kortessluoma et al., 2008) [U]**

*Illustration:*

“Sometimes I bite that Moomin’s (a soft toy) leg. It kind of helps. It feels as if it helps”. (p. 149)

**Finding 13: Actions adolescents’ recalled using to manage pain (Crandall et al., 2002) [U]**

*Illustration:*

“I wouldn’t think about my leg too much. I’d concentrate on something else. Cause if you think about whatever hurts and you think about it too much, you’ll hurt more. So just try to keep your mind off of it.” (p.108)

**Finding 14: Participation ( Nilsson et al., 2011b) [U]**

*Illustration:*

“Decided whether I should get a blue or a red plaster.” (p.1454)

**Finding 15: Nothing can help (Kortessluoma et al., 2008) [U]**

*Illustration:*

“When I have this terrible headache and it’s not going to get better, I feel like it’s hurting all the time and no one can do anything. It gets better when it is meant to.”(p.147)

## **Category 2.2 Feeling secure**

Children of all ages needed to feel secure as a form of comfort when they were in pain. Feelings of security emerged when a child felt safe within their environment, this involved having familiar people with them, as well as establishing trusting relationships with healthcare professionals.

### **Finding 16: Security (Nilsson et al., 2011b) [C]**

#### *Illustration:*

“It is fun to come to the hospital; you can do a lot of things.” (p.1454)

### **Finding 17: Significant others as helpers (Kortessluoma et al., 2008) [C]**

#### *Illustration:*

“Yeah, someone somehow-usually my mother, in my opinion, maybe my father and brother too”. (p.146)

### **Finding 18: Other generated sources of pain relief (Kortessluoma et al., 2008) [U]**

#### *Illustration:*

“In my opinion it is very important that someone is close to you when you are in pain... normally my mom... nurses-not all of them. Those who are gentle or those who stay a while with you, they can.” (p. 146)

## **Category 2.3 Actions of others to help manage children’s pain**

Children sought comfort in the action and presence of others when they were in pain. Children expressed needing their family and friends with them for a variety of different reasons such as providing emotional support, providing information and helping with daily activities. Children also expressed that healthcare professionals, namely nurses, played a pivotal role in helping them when they were in pain.

### **Finding 19: Distraction (Nilsson et al., 2011) [U]**

#### *Illustration:*

“The lollipop made me feels calm.” (p.1453)

**Finding 20: Expectations of professional help (Kortelnuoma et al., 2008) [U]**

*Illustration:*

“Well, I don’t know, they (nurses) can’t help so much. But maybe they can... They are not like those close to you who are able to do everything. But the tough nurses can’t help. They think that they can explain everything... but it doesn’t help the pain.” (p.146)

**Finding 21: Clinical competence (Nilsson et al., 2011b) [U]**

*Illustration:*

“When the bandage was caught the nurse did not just pull, she used the salve.” (p.1453)

## **Appendix G JBI Levels of Evidence**

### **Levels of Evidence for Meaningfulness**

1. Qualitative or mixed-methods systematic review
2. Qualitative or mixed –methods synthesis
3. Single qualitative study
4. Systematic review of expert opinion
5. Expert opinion

(Joanna Briggs Institute, 2014b)

## Appendix H Information Sheet for Parents



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



Curtin University

### **Giving Children a voice: Children's perceptions of pain and pain management within the Paediatric Emergency Department; A mixed methods study**

#### **Why are we doing the study?**

Children that are brought into a hospital's Emergency Department (ED) are often in pain. Pain is usually a very upsetting and unpleasant experience. One of the important jobs hospital staff at Princess Margaret Hospital for Children (PMH) have is to help lessen the pain a child is experiencing. We would like to know how well we are doing at relieving children's pain, one of the best ways to find out this is to ask the children.

#### **What will the study tell us?**

We hope it will give us a better understanding of children's pain and tell us if we are doing a good job at helping relieve their pain. What we find out will help us improve the way we manage children's pain.

#### **Who is carrying out the study?**

A Registered Nurse will be doing the study as part of a Master's research degree through Curtin University. Other experienced nurses and researchers will also be helping.

#### **Does my child have to take part?**

No, your child does not have to take part. If you and/or your child do not want to take part it will not affect the care your child will receive.

#### **What will you and your child be asked to do if you decide to take part in this study?**

You will be asked to sign a 'form of consent' which says that you agree that your child can be part of the study, and that the researcher can access your child's hospital clinical notes. After you are seen by the triage nurse, the researcher will score your child's pain using two different techniques. One involves looking at your child's facial expressions and body language, and the other uses a picture of six different faces (see below). Your child will be asked to point to the face that shows how bad their pain is. Both of these scoring techniques will be used again before you and your child leave ED. We would expect to see your child's pain improve before going home.



Before you and your child leave ED, the researcher will arrange a time and a place that would suit you to ask your child a few questions about their pain. This can either be in a private place in the ED, or anywhere that would suit you. In this interview your child will also be asked to draw a picture about their pain and describe their picture to the researcher. This will take about one hour.

**What does my child need to do to be in the study?**

Where possible, we would like your child to decide if he/she wants to be part of the study, its ok if you or your child change your mind at any time. Your child needs to be between 4 and 8 years old and be able to speak English so that they can answer the researcher's questions. Your child's medical needs are the most important thing, so if at any time they are considered too sick, they might not be able to take part in the study.

**Is there likely to be a benefit to my child?**

No, there is not likely to be any benefit to your child by being in this study.

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

Yes. At PMH our main priority is providing the best care to children and their families, and we are always looking for ways to improve care. Therefore if the results of this study show that children's pain could have been better managed, hospital staff and future studies will look at different ways to improve how children's pain is treated at PMH in the future.

Once the research is complete, estimated by December 2016, the results and findings of the research will be provided to you if you wish. Please provide me with details of where and how to send the results of the study (email address or postal address).

**What are the possible risks, side effects and/or inconveniences?**

No risks are associated with assessing your child's pain. The scales used to score your child's pain have all been used at PMH for some time. Similar interview questions have been asked in other studies, and have not shown any risks or side effects. If your child was to unexpectedly feel upset or react in a bad way when they answer the questions, the researcher may have to stop the interview either temporarily or altogether. The researcher can assist you and your child by providing information of further support.



**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.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR46/2015) and the Princess Margaret Hospital for Children Human Research Ethics Committee (Approval Number 2014082EP). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au)

**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**

The researcher will work with you to arrange a time and place that is convenient, to ask your child the interview questions. This needs to be within 48hrs after leaving ED, and you can change your mind about the time and location.

If your child needs to stay in hospital, the researcher can arrange a suitable time to visit you while you are still in the hospital, as long as it is within 48hrs.

**Where is your information kept?**

The paper copy of the data collected and all documents will be kept in a locked filing cabinet in a secure office at PMH, these will be archived indefinitely. Computer data will not have any identifying names, will be password protect and able to be accessed by the research team only.

**What about my privacy?**

Information will remain confidential. Each child will receive a study code which will be used on all paperwork. The only information that will be collected about your child will be their date of birth, sex, and pain scores which we need to make sure your child is suitable for the study. The interviews will be recorded using a voice recorder. Recorded conversations will then be typed out word for word so that we can listen to the interview and use this to learn about your child's pain experience. These recordings will only be heard by the researcher(s) and your child's identity will remain confidential. A pseudonym will replace your child's name when being typed, and once typing is complete, the recordings will be destroyed. When results of this study are made public you and your child's name will not appear on the report.

**Who has approved the study?**

It has been approved by the Human Research Ethics Committee at PMH and Curtin University. The ED staff are aware of the study, and both the Nurse Manager of the ED and the pain specialist nurse have also approved the study.

**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 one of the research team. They are very happy to answer your questions.

Name	Title	Contact Number
Nicole Pope	Registered Nurse & Curtin University Student	TBA
Sally Wilson	Nurse Researcher	TBA
Mary Tallon	Lecturer; Curtin University	TBA

# Appendix I Information Sheet for Children



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



Curtin University

## Giving Children a voice: Children's perceptions of pain and pain management within the Paediatric Emergency Department; A mixed methods study

### Why are we doing the study?

Sometimes when kids come to hospital they hurt somewhere. Hurting isn't nice. Doctors and nurses want to know when kids are hurting, and how to help make it better.

### What will the study find out?

We will find out about when kids are hurting, and how we can help make the hurt go away.

### Who is doing the study?

A nurse who is going to University will be doing the study; lots of other nurses will also help.

### Do I have to be in the study?

No, you do not have to be in the study. Only do the study if you want to and if a grown up that usually looks after you says it's ok.

### What will I have to do if I'm in the study?



First we show you these faces



And you can point to the face that shows how bad you hurt



Other nurses and doctors will come and speak to you and make sure you are ok



Just before you go, we will show you the faces again so you can point at what face shows how bad you hurt



We will come and see you after you leave the hospital to ask you some things about how you were hurting when you were in hospital, and what helped when it hurt. You will also get to draw a picture.

We are going to tape all the things you and the researcher say to each other with a little recording machine.

**Is the study going to help me?**

Maybe not right now, but we might be able to find out better ways to help if you are hurting again

**Is the study going to help other kids?**

Yes, we hope so. If we find out better ways to help when something hurts, we can help other kids too.

**Could the study be dangerous, or make the hurt worse?**

No, the study will not be dangerous, or make your hurt worse.

We will talk to you and the grown up who looks after you so that we can make a time to come and see you after you leave hospital. We will try to make sure it doesn't interrupt your school or any other things that you normally do.

If you feel upset when you are doing the study, we will talk with you and the grown up about how we can help you feel better.

**Where are all the notes with my name on it kept?**

We are not going to use your real name on any of the notes, we will use a special number instead. You get to choose a pretend name instead of your real name when we are talking to each other. We will write everything that you and the researcher talk about like a story, when all the words have been written down, we will delete the tape. All the notes will be locked away.

**Who said it was ok to do the study?**

A group of people who have the job of making sure studies are not dangerous for kids said that it was ok to do this study. Other nurses also said that the study is ok to do.

**Who do I talk to if I want to know more about the study, or even if I am upset?**

You can ask the grown up that usually looks after you and the researcher.

If you are upset or not happy it is very important you tell the grown up that normal looks after you.

## Appendix J Consent Form



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



**Curtin University**

### FORM OF CONSENT (For Parent/Guardian)

**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

.....

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

I agree to allow

.....

(full name of participant and relationship of participant to signatory)

to participate in the study.

I agree to the researcher(s) having access to my child's hospital clinical records for the purpose of this study.

I understand my child 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 .....

Child's Signature .....  
(Where appropriate)

Parent or Guardian's Signature .....

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

signatories who stated that he/she understood the same.

Signature .....

Form of Consent from Protocol Version 3 Dated 2 October 2014

# Appendix K Data Collection Form



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



**Curtin University**

Date: \_\_\_\_\_; Time: \_\_\_\_\_ hrs;

Date of Birth      Age:

Sex:

Participant study number:

Past medical history

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Reason for ED presentation:

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Primary source of pain (identified by the child):

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FLACC score on first assessment: Time: \_\_\_\_\_ hrs

1    2    3    4    5    6    7    8    9    10

FPS-R score on first assessment: Time: \_\_\_\_\_ hrs

1    2    3    4    5    6    7    8    9    10

Treatment received within the ED:

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Analgesia received within the ED:

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FLACC score on ED discharge assessment: Time: \_\_\_\_\_ hrs

1    2    3    4    5    6    7    8    9    10

FPS-R score on ED discharge assessment: Time: \_\_\_\_\_ hrs

Diagnosis at discharge:

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Follow-up interview arrangements: *(eg. Date, time, location, contact details)*

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# Appendix L Child and Adolescent Health Service Human Research Ethics Approval



Government of **Western Australia**  
Department of **Health**  
Child and Adolescent Health Service  
**Research Governance Office**

Our Ref: 2014082EP

Dr Sally Wilson  
Nursing Research, Level 6  
Hay St Building  
Princess Margaret Hospital  
Subiaco WA 6008

Dear Dr Wilson

**HREC REF** 2014082EP  
**STUDY TITLE** Giving them a voice: Children's perceptions of pain and pain management  
within the Paediatric Emergency Department; A mixed Methods Study

On behalf of the Child and Adolescent Health Service, I give authorisation for your research project to be conducted at the following site(s):

Princess Margaret Hospital for Children - CAHS

This authorisation is based on the approval from PMH HREC and the review from the Research Governance Office. This authorisation is valid subject to the ongoing approval from the HREC.

This authorisation is based on the ethical approval from the HREC, and on the basis of compliance with the 'Conditions of Authorisation to Conduct a Research Project at Site' (attached) and with the compliance of all reports as required by the Research Governance Office and approving HREC. Non compliance with these requirements could result in the authorisation being withdrawn.

The responsibility for the conduct of this project remains with you as the Principal Investigator at the site.

Yours sincerely

Dr Mark Salmon  
Executive Director  
Medical Services

18/11/2014





## **CONDITIONS OF SITE AUTHORISATION TO CONDUCT A RESEARCH PROJECT**

The following general conditions apply to the research project authorised to be conducted at the site(s) nominated in the accompanying letter. The acceptance of the site authorisation will be deemed to be an acceptance of these conditions by all investigators involved in the research project at the nominated site(s).

1. The responsibility for the conduct of project at a site lies with the nominated Principal Investigator (PI) at that site, all correspondence should be signed by PI.
2. The PI will inform the Research Governance Office (RGO) about any changes to the project. The PI is responsible for submitting any amendments to the approved documents listed on the approval letter, or any new documentation to be used in the project. Any new or amended documentation should be submitted in a timely manner and cannot be implemented at this site until they have received HREC approval for use at site(s).
3. The PI will notify the RGO of their inability to continue as PI at the site(s) and will provide the name and contact information of their replacement.
4. The PI will notify the RGO of any departures of named site investigators. The PI will also notify the RGO if any new site investigators join the project.
5. The PI is responsible for reporting site adverse events, using the standard forms available from the website. Reporting requirements are as per the WA Health Research Governance and Single Ethical Review Standard Operating Procedures. Additional reports, other than those outlined, that are submitted will be returned without acknowledgement.
6. The annual report that is submitted to the HREC should also be submitted to the RGO. This should include the site specific information which should be completed by the site PI.
7. The site has the authority to audit the conduct of any project without notice. Exercise of this authority will only be considered if there are grounds to believe that some irregularity has occurred, if a complaint is received from a third party or the site decides to undertake an audit for Quality Improvement purposes.
8. The site can conduct random monitoring of any project. The PI will be notified if their project has been selected. The PI will be given a copy

of the monitor's report along with the HREC and RGO.

9. Complaints relating to the conduct of a project should be directed to the RGO and will be promptly investigated according to the site Standard Operating Procedures.
10. The PI is reminded that records of consent or authorisation for participation in a project form part of the Acute Hospital Patient Record and should be stored with that record in accordance with the *WA Health Patient Information Retention and Disposal Schedule (Version 2) 2000*. A copy of the 'Participant Information Sheet' should also be included in the medical records as part of informed consent documentation.
11. Once the project has been closed at site, the PI is required to submit to the RGO a copy of the final report that is submitted to the HREC. This should include the site specific information which should be completed by the site PI. If the report is not received within 30 days the project will be closed and archived. An outstanding final report could impact on the PI's ability to apply for approval for future projects.
12. If a project is suspended or terminated the PI must ensure that the RGO at site is informed of this and the circumstances necessitating the suspension or termination of the project. Such notification should include information as to what procedures are in place to safeguard participants.
13. If a project fails to meet these conditions the RGO will contact the investigator(s) to request they rectify the identified issues. If, after being contacted by the RGO, the issues are not addressed the site authorisation will be withdrawn.



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

Our Ref: 2014082EP

Dr Sally Wilson  
Nursing Research, Level 6  
Hay St Building  
Princess Margaret Hospital  
Subiaco WA 6008

Dear Dr Wilson

**HUMAN RESEARCH ETHICS COMMITTEE (HREC)**

**HREC REF** 2014082EP

**STUDY TITLE** Giving them a voice: Children's perceptions of pain and pain management within the Paediatric Emergency Department; A mixed Methods Study

The ethics application for the project referenced above was reviewed by the PMH Human Research Ethics Committee (HREC) at its meeting on 16/10/2014. It has been approved and the following documents have been approved for use in this project.

WA Ethic Application Form Version 3 dated 2 October 2014  
Information sheet for kids Version 4 dated 2 October 2014  
Parent Information Sheet Version 4 dated 2 October 2014  
Consent Form for Parent/Guardian  
Protocol form 4B Version 2 April 2010  
Protocol Version 3 dated 2 October 2014

Approval of this project from PMH HREC is valid to and on the basis of compliance with the 'Conditions of HREC Approval for a Research Project' (attached).

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

A copy of this ethical approval letter must be submitted by all site Principal Investigators to the Research Governance Office or equivalent body or individual at each participating institution in a timely manner to enable the institution to authorise the commencement of the project at its site/s.

**This letter constitutes ethical approval only.**

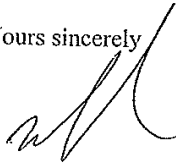
This project cannot proceed at any site until separate site authorisation has been obtained from the CE, or delegate, of the site under whose auspices the research will be conducted at that site.

The PMH HREC is registered with the Australian Health Ethics Committee and operates according to the NHMRC National Statement on Ethical Conduct in Human Research and International Conference on Harmonisation – Good Clinical Practice.

The HREC's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from <http://www.pmh.health.wa.gov.au/development/resources/ethics.htm> or from the Ethics Office. Should you have any queries about the HREC's consideration of your project, please contact Ethics Office.

Please quote the above trial number 2014082EP on all correspondence associated with this trial.

Yours sincerely



Dr Mark Salmon  
Executive Director  
Medical Services

17/11/2014

\* 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




## CONDITIONS OF HREC APPROVAL FOR A RESEARCH PROJECT

The following general conditions apply to the research project approved by the Human Research Ethics Committee (HREC) and acceptance of the approval will be deemed to be an acceptance of these conditions by all investigators involved in the research project:

1. The responsibility for the conduct of projects lies with the Coordinating Principal Investigator (CPI), all correspondence should be signed by CPI.
2. Projects that do not commence within 12 months of the approval date may have their approval withdrawn and the project closed. The CPI must outline why the project approval should stand.
3. The submission of an application for HREC approval will be deemed to indicate that the investigator/s and any sponsor recognises the approving HREC is registered with the National Health and Medical Research Council (NHMRC) and that it complies in all respects with the National Statement on Ethical Conduct in Human Research and all other national and international ethical requirements. **The HREC will not enter into further correspondence on this point.**
4. A list of attendance at a specific meeting is available on request, but no voting records will be provided.
5. The CPI will notify the HREC of his or her inability to continue as CPI and will provide the name and contact information of their replacement. Failure to notify the HREC can result in the project being suspended or approval withdrawn.
6. The CPI will notify the HREC of any departures of named investigators. The CPI will also notify the HREC if any new investigators and/or sites join the project that will utilise the HREC's approval.
7. The CPI will inform the HREC about any changes to the project. The CPI is responsible for submitting any amendments to the approved documents listed on the approval letter, or any new documentation to be used in the project. Any new or amended documentation should be submitted in a timely manner and cannot be implemented at any participating site until they have received HREC approval.
8. The CPI is responsible for reporting adverse events, indicating whether or not the project should continue. Reporting requirements are as per the WA Health Research Governance and Single Ethical Review Standard Operating Procedures. Additional reports other than those outlined that are submitted to the HREC will be returned without acknowledgement. The HREC can request additional reporting requirements as a special condition of a research project.
9. Where a project requires a Data Safety Monitoring Board (DSMB) it is the CPI's responsibility to ensure this is in place before the commencement of the project and the HREC notified of this. All relevant reports from the DSMB should be submitted to HREC.
10. For projects where the site is acting as the sponsor (ie. investigator initiated project) it is the responsibility of the CPI to report serious and unexpected drug/device reactions, as well as other reactions/events to the Therapeutic Goods Administration (TGA). Please refer to TGA website for further information and the relevant forms (see <http://www.tga.gov.au/pdf/clinical-trials-guidelines.pdf> p71 for medications or p77 for devices).
11. If this project involves the use of an implantable device a properly monitored and up to date system for tracking participants is to be maintained for the life of the device in accordance with the National Statement section 3.3.22 (g).

12. The investigator is responsible for notifying the Therapeutic Drugs Administration of a device incident in accordance with the National Statement section 3.3.22 (g).
13. An annual report on an approved research project will be required on the anniversary date of the project's approval. HREC approvals are subject to the submission of these reports and approval may be suspended if the report is not submitted.
14. The HREC has the authority to audit the conduct of any project without notice. Exercise of this authority will only be considered if there are grounds to believe that some irregularity has occurred, if a complaint is received from a third party or the HREC decides to undertake an audit for Quality Improvement purposes.
15. The HREC can conduct random monitoring of any project. The CPI will be notified if their project has been selected. The CPI will be given a copy of the monitor's report along with the HREC and Research Governance Office (RGO) at each site.
16. Complaints relating to the conduct of a project should be directed to the HREC Chair and will be promptly investigated according to the Committee's complaints procedures.
17. CPI are reminded that records of consent or authorisation for participation in a project form part of the Acute Hospital Patient Record and should be stored with that record in accordance with the *WA Health Patient Information Retention and Disposal Schedule (Version 2) 2000*. A copy of the 'Participant Information Sheet' should also be included in the medical records as part of informed consent documentation.
18. The duration of HREC approval for a project is 3 year (with the option of 5 years) from the date of approval. The date of approval expiry is stipulated in the HREC approval letter.
19. If the project is to continue beyond the stipulated approval expiry date a request for an extension should be submitted prior to that expiry date. One extension of 3 years can be granted but approval beyond this time period may necessitate further review by the HREC.
20. Once the approval period has expired, the CPI is required to submit a final report. If the report is not received within 30 days the project will be closed and archived. An outstanding final report could impact on the CPI's ability to apply for approval for future projects.
21. If a project is suspended or terminated by the CPI, or a project sponsor, the CPI must immediately inform the HREC and the RGO at each site of this and the circumstances necessitating the suspension or termination of the project. Such notification should include information as to what procedures are in place to safeguard participants.
22. If a project fails to meet these conditions the HREC will contact the investigator(s) to request they rectify the identified issues. If, after being contacted by the HREC, the issues are not addressed the HREC approval will be withdrawn. The HREC will notify the RGO at each site within WA Health that work may no longer be conducted in relation to the project other than that concerning the participants safety.

# Appendix M Curtin University Human Research Ethics Approval

MEMORANDUM		 Curtin University
To:	Dr Ruth McConigley School of Nursing and Midwifery	Office of Research and Development Human Research Ethics Office
CC:		
From:	Professor Peter O'Leary, Chair HREC	TELEPHONE 9266 2784 FACSIMILE 9266 3793 EMAIL hrec@curtin.edu.au
Subject:	Reciprocal ethics approval Approval number: HR46/2015	
Date:	12-Mar-15	

Thank you for your application submitted to the Human Research Ethics Office for the project: 6089  
Giving Children a Voice: Children's Perceptions of Pain and Management within the Paediatric  
Emergency Department; A mixed Methods Study

Your application has been approved through Curtin University Human Research Ethics Committee (HREC)  
through a reciprocal approval process with the lead HREC.

The lead HREC for this project has been identified as Princess Margaret Hospital for Children HREC


Approval number from the lead HREC is noted as: 2014082EP

Please note the following conditions of approval:

1. Approval is granted from **17-Mar-15** to **17-Mar-19**
2. Research must be conducted as stated in the approved protocol.
3. Any amendments to the approved protocol must be approved by the Ethics Office.
4. An annual progress report must be submitted to the Ethics Office annually, on the anniversary of approval.
5. All adverse events must be reported to the Ethics Office.
6. A completion report must be submitted to the Ethics Office on completion of the project.
7. Data must be stored in accordance with WAUSDA and Curtin University policy.
8. The Ethics Office may conduct a randomly identified audit of a proportion of research projects approved by the HREC.

Should you have any queries about the consideration of your project please contact the Ethics Support Officer for your faculty, or the Ethics Office at hrec@curtin.edu.au or on 9266 2784. All human research ethics forms and guidelines are available on the ethics website.

Yours sincerely,



Professor Peter O'Leary  
Chair, Human Research Ethics Committee

# Appendix N Copyright Permission from Peer Reviewed Journals

## Joanna Briggs Institute

09<sup>th</sup> October 2017

Dear Ms Fletcher,

It is my understanding that JBI are the copyright holder for the following materials:

Manuscripts:

Pope, N., Tallon, M., Leslie, G., Wilson, S. (2017). Why we need to research with children, not on children. *JBI Database of Systematic Reviews and Implementation Reports*, 15(6), 1497-1498. DOI: 10.11124/jbisrir-2017-003458

Pope, N., Tallon, M., McConigley, R., Leslie, G., & Wilson, S. (2017). The experiences of acute pain of children who present to a healthcare facility for treatment: a systematic review of qualitative evidence. *JBI Database of Systematic Reviews & Implementation Reports*, 6 (15), 1612-1644. DOI: 10.11124/JBISRIR-2016-003029

Pope, N., Tallon, M., McConigley, R., & Wilson, S. (2015). The experiences of acute non-surgical pain of children who present to a healthcare facility for treatment: a systematic review protocol. *JBI Database of Systematic Reviews & Implementation Reports*, 13 (10), 12-20. DOI: 10.11124/jbisrir-2015-2466

I would like to reproduce an extract of these manuscripts in a Master's thesis which I am currently undertaking at Curtin University in Perth, Western Australia. The subject of my research is exploring children's pain experiences. I am carrying out this research in my own right and have no association with any commercial organisation or sponsor.

The specific material that I would like to use for the purposes of the thesis are the manuscripts, which will be presented within the thesis, with full acknowledgement of the ownership of the copyright.

Once completed, the thesis will be made available in online form via Curtin University's Institutional Repository espace (<http://espace.curtin.edu.au>). The material will be provided strictly for educational purposes and on a non-commercial basis.

I would be most grateful for your consent to the copying and communication of the work as proposed. If you are willing to grant this consent, please complete and sign the attached approval slip and return it to me via email and/or at the address shown. Full acknowledgement of the ownership of the copyright and the source of the material will be provided with the material.

If you are not the copyright owner of the material in question, I would be grateful for any information you can provide as to who is likely to hold the copyright.

I look forward to hearing from you and thank you in advance for your consideration of my request.

Yours sincerely



Nicole Pope



**PERMISSION TO USE COPYRIGHT MATERIAL AS SPECIFIED BELOW:**

Manuscript: Using 'draw, write and tell' to understand children's health related experiences: Learning with children through research

I hereby give permission for Nicole Pope to include the abovementioned material(s) in his/her higher degree thesis for Curtin University, and to communicate this material via the espace institutional repository. This permission is granted on a non-exclusive basis and for an indefinite period.

I confirm that I am the copyright owner of the specified material.

Signed: 

Name: Edoardo Aronateris

Position: Director, Synthesis Science / Editor-in-Chief, JBISRIR

Date: 9/10/17

Please return signed form via email to [Nicole.pope@curtin.edu.au](mailto:Nicole.pope@curtin.edu.au)

Or postal address to

Nicole Pope

School of Nursing, Midwifery and Paramedicine  
Curtin University  
GPO Box U1987,  
Perth WA 6845

## Nurse Researcher

### *Email Correspondence*

**From:** Jessica Rutt <[jessica.rutt@rcni.com](mailto:jessica.rutt@rcni.com)>  
**Sent:** Monday, 9 October 2017 4:26 PM  
**To:** Nicole Pope  
**Subject:** RE: Permission Request manuscript - NR1594R1

Dear Nicole,

Thank you for your enquiry. I'm happy to grant permission for this reuse of your article in your thesis. Please be sure to acknowledge Nurse Researcher as the original publisher of your work.

Best,  
Jessica

**Jessica Rutt**  
International Rights and Licensing Manager  
T +44 (0)20 8423 1333  
E [jessica.rutt@rcni.com](mailto:jessica.rutt@rcni.com)  
W [rcni.com](http://rcni.com)



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---

**From:** Liz Halcomb [<mailto:ehalcomb@uow.edu.au>]  
**Sent:** 08 October 2017 01:16  
**To:** Helen Hyland <[helen.hyland@rcni.com](mailto:helen.hyland@rcni.com)>  
**Subject:** FW: Permission Request manuscript - NR1594R1

Hi Helen  
Can you assist Nicole in gaining permission?

*Liz*

**Dr Elizabeth Halcomb RN BN(Hons) GCertHE GCertICNurs PhD FACN**  
Professor of Primary Health Care Nursing  
BN Honours Co-Ordinator  
Subject Co-Ordinator SNPG915

Editor, Nurse Researcher  
Editor, Collegian: The Australian Journal of Nursing Practice, Scholarship and Research  
Associate Editor, BMC Family Practice  
Editorial Board, Australian Journal of Primary Health

School of Nursing | Faculty of Science, Medicine & Health | Room 108 Building 41  
University of Wollongong NSW 2522 Australia  
T +61 2 4221 3784 | E [ehalcomb@uow.edu.au](mailto:ehalcomb@uow.edu.au)

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AUSTRALIA



University of Wollongong CRICOS: 00102E

Your feedback is appreciated and can be submitted at: [feedback@uow.edu.au](mailto:feedback@uow.edu.au)

NOTICE: This email is intended for the addressee name and may contain confidential information. If you are not the intended recipient, please delete it and notify the sender. Please consider the environment before printing this email.

---

**From:** Nicole Pope [<mailto:nicole.pope@curtin.edu.au>]

**Sent:** Sunday, 8 October 2017 10:50 AM

**To:** Liz Halcomb <[ehalcomb@uow.edu.au](mailto:ehalcomb@uow.edu.au)>

**Subject:** Permission Request manuscript - NR1594R1

Dear Dr Halcomb,

It is my understanding that Nurse Researcher are the copyright holder for the following material:

Manuscript:

Using 'draw, write and tell' to understand children's health related experiences: Learning with children through research

I would like to reproduce an extract of this work in a Master's thesis which I am currently undertaking at Curtin University in Perth, Western Australia. The subject of my research is

exploring children's pain experiences. I am carrying out this research in my own right and have no association with any commercial organisation or sponsor.

The specific material that I would like to use for the purposes of the thesis is the manuscript, which will be presented within the thesis, with full acknowledgement of the ownership of the copyright.

Once completed, the thesis will be made available in online form via Curtin University's Institutional Repository espace (<http://espace.curtin.edu.au>). The material will be provided strictly for educational purposes and on a non-commercial basis.

I would be most grateful for your consent to the copying and communication of the work as proposed. If you are willing to grant this consent, please complete and sign the attached approval slip (page 2) and return it to me via email and/or at the address shown. Full acknowledgement of the ownership of the copyright and the source of the material will be provided with the material.

If you are not the copyright owner of the material in question, I would be grateful for any information you can provide as to who is likely to hold the copyright.

I look forward to hearing from you and thank you in advance for your consideration of my request.

Yours sincerely,

**Nicole Pope**

BN, GradCert(PubHlth), GradCert(PaedNurs), MPhil (Candidate)  
Unit Coordinator NURS1000

Workdays: Monday, Wednesday, Thursday and Friday (not Tuesday)

Lecturer | School of Nursing, Midwifery & Paramedicine  
Faculty of Health Sciences

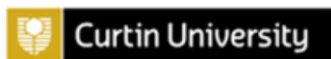
*"ERA 5 for Research Excellence and QS top 100 subject world ranking."*

Curtin University

Tel | +61 8 9266 2216

Email | [nicole.pope@curtin.edu.au](mailto:nicole.pope@curtin.edu.au)

Web | <http://curtin.edu.au>



CRICOS Provider Code 00301J

## Journal for Specialists in Pediatric Nursing

### *Email Correspondence*

**From:** Ryan-Wenger, Nancy <[ryan-wenger.10@osu.edu](mailto:ryan-wenger.10@osu.edu)>  
**Sent:** Wednesday, 25 April 2018 8:58 PM  
**To:** Nicole Pope  
**Subject:** RE: Copyright Permission Request

Hello, Nicole!

I just accepted your manuscript for publication in the Journal for Specialists in Pediatric Nursing. Congratulations!

Regarding your question about submitting your thesis to Curtin University's Institutional Repository espace:

This procedure is common among most Universities and does not represent a copyright issue for future publication in peer-reviewed journals, nor is your manuscript considered a duplicate publication. Therefore, I do not need to sign the form that you attached.

In my letter to you, I congratulated you on your new PhD. I realize now that you will receive a Masters degree. Congratulations! Perhaps you will consider a PhD in the future.

Nancy

Nancy A. Ryan-Wenger, PhD, RN, CPNP, FAAN

Editor-in-Chief, *Journal for Specialists in Pediatric Nursing*  
[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1744-6155](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1744-6155)

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Generational differences in the sexual communication process of African American grandparent and parent caregivers of adolescents NEW

Nancy A. Ryan-Wenger Consulting, LLC  
5029 Mason Road  
Canal Winchester, OH 43110

Phone: 614-302-1701  
Fax: 614-792-9110  
e-mail: [ryan-wenger.10@osu.edu](mailto:ryan-wenger.10@osu.edu)

Professor Emeritus  
The Ohio State University

---

**From:** Nicole Pope [[nicole.pope@curtin.edu.au](mailto:nicole.pope@curtin.edu.au)]  
**Sent:** Monday, April 23, 2018 10:39 PM

**To:** Ryan-Wenger, Nancy  
**Subject:** Copyright Permission Request

Dear Prof. Ryan-Wenger,

It is my understanding that the Journal for Specialists in Pediatric Nursing may become the copyright holder for the following material (awaiting a decision):

Manuscript ID JSPN-OM-18-017

"Ask me: Children's Experiences of Pain Explored using Draw, Write and Tell".

I would like to reproduce an extract of this manuscript in a Masters thesis which I am currently undertaking at Curtin University in Perth, Western Australia. I will be submitting this thesis in by the 4th of May 2018. The subject of my research is exploring children's pain experiences. I am carrying out this research in my own right and have no association with any commercial organisation or sponsor.

The specific material that I would like to use for the purposes of the thesis is the manuscript submitted awaiting your journal's decision, which will be presented within the thesis with full acknowledgement of the ownership of the copyright.

Once completed, the thesis will be made available in online form via Curtin University's Institutional Repository espace (<http://espace.curtin.edu.au>). The material will be provided strictly for educational purposes and on a non-commercial basis.

I would be most grateful for your consent to the copying and communication of the work as proposed. If you are willing to grant this consent, please complete and sign the attached approval slip on page two of the attachment in this email, and return it to me via email. Full acknowledgement of the ownership of the copyright and the source of the material will be provided with the material.

If you are not the copyright owner of the material in question, I would be grateful for any information you can provide as to who is likely to hold the copyright.

I look forward to hearing from you and thank you in advance for your consideration of my request.

Yours sincerely,

Nicole Pope

BN, GradCert(PubHlth), GradCert(PaedNurs), Mphil Candidate

School of Nursing, Midwifery and Paramedicine

Faculty of Health Sciences

Curtin University

PH: 0400 981 610

## Appendix O Statement of Contributors

### Manuscript Presented in Chapter 3

Title: The experiences of acute pain of children who present to a healthcare facility for treatment: a systematic review of qualitative evidence.

Citation details: Pope, N., Tallon, M., McConigley, R., Leslie, G., & Wilson, S. (2017). The experiences of acute pain of children who present to a healthcare facility for treatment: a systematic review of qualitative evidence. *JBIR Database of Systematic Reviews & Implementation Reports*, 6 (15), 1612–1644. DOI: 10.11124/JBIRSRIR-2016-003029.

Status: Published in *JBIR Database of Systematic Reviews & Implementation Reports*, 6 (15), 1612–1644. DOI: 10.11124/JBIRSRIR-2016-003029

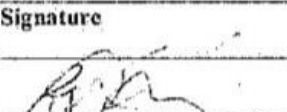
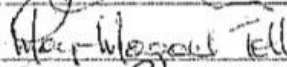
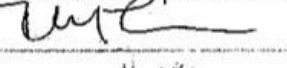
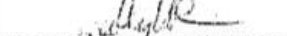
I, Nicole Pope, authored the above manuscript with support and assistance from the co-authors.



Nicole Pope

06/03/2018

As co-author, I endorse that the level of contribution by the candidate indicated above is true and appropriate.

Name	Signature	Date
Professor Gavin Leslie		06/03/2018
Dr Mary Tallon	 Mary Tallon	06/03/2018
Dr Ruth McConigley		19.3.2018
Dr Sally Wilson		11/3/2018

## Manuscript Presented in Chapter 5

Title: Using 'draw, write and tell' to understand children's health related experiences: Learning with children through research.

Citation details: Pope, N., Tallon, M., Leslie, G., Wilson, S. (2017). Using 'draw, write and tell' to understand children's health related experiences: Learning with children through research.

Status: Accepted for publication in *Nurse Researcher*.

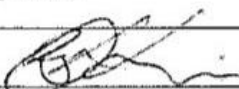
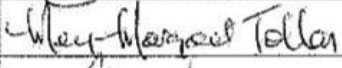

I, Nicole Pope, authored the above manuscript with support and assistance from the co-authors.



Nicole Pope

06/03/2018

As co-author, I endorse that the level of contribution by the candidate indicated above is true and appropriate.

Name	Signature	Date
Professor Gavin Leslie		06/03/2018
Dr Mary Tallon		06/03/2018
Dr Sally Wilson		11/3/2018




## Manuscript Presented in Chapter 6

Title: Ask me: Children's experiences of pain explored using the draw, write and tell method

Citation details: Pope, N., Tallon, M., Leslie, G., Wilson, S. (2018). Ask me: Children's experiences of pain explored using draw, write and tell.

Status: Accepted for publication: *Journal for Specialists in Pediatric Nursing*

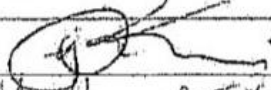
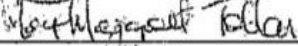

I, Nicole Pope, authored the above manuscript in support and assistance from the co-authors.



Nicole Pope

06/03/2018

As co-author, I endorse that the level of contribution by the candidate indicated above is true and appropriate.

Name	Signature	Date
Professor Gavin Leslie		06/03/2018
Dr Mary Tallon	 Mary Margaret Tallon	06/03/2018
Dr Sally Wilson		11/3/2018