University of Alberta

Acute Pain in Hospitalized Chronically Ill Children

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master in Nursing

Faculty of Nursing

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Spring 2012
Edmonton, Alberta

Abstract

An exploration and analysis of hospitalized children's experience of acute pain, when diagnosed with a chronic illness. The first study is an integrated review of the available literature related to the prevalence and experiences of children with a chronic diagnosis, their experiences with acute pain and assessment measures while in hospital. The second study utilized an established database and secondary analysis to examine the incidence and frequency of chronic diagnosis, painful procedures, and pain assessments experienced by Canadian children while in hospital. Findings included 35.7% of hospitalized Canadian children had a chronic diagnosis. These children were found to receive an increased number of painful procedures in a 24 hour period, yet they did not receive an increase in assessment of their pain. Chronically ill Canadian children where found to experience a painful procedure 86% of the time while in hospital, yet only 68% of these received a pain assessment.

Acknowledgement

I would like to acknowledge several individuals and organizations whose efforts have contributed to the successful completion of my graduate degree:

Financially, I have been supported by the Canadian Institute for Health Research (CIHR) Team in Children's Pain, and the Faculty of Graduate Studies and Research at the University of Alberta. Their support was instrumental in providing me with the opportunity to pursue my academic goals.

I would like to express my heartfelt appreciation to my thesis committee members: Dr. Dawn Davies and Kathy Reid RN, MN PNP. I am very greatful for their insightful suggestions and comments, as well as for their help and support.

Finally, I would like to thank Shannon Scott RN, PhD, my thesis supervisor. I owe a debt of gratitude to her for her unfailing support, her belief in my abilities and her consistent guidance and support during my entire academic career. My sincere thanks Shannon.

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Chapter 1: Introduction

Hospitalized Chronically Ill Children's Experience of Acute Pain

This thesis is an outcome of my master's program of research that focused on the experience of acute pain in children with a chronic diagnosis. The purpose of my research was to develop and utilize a generalized, yet specific approach to categorize chronic illnesses in children. This approach allowed for clear, consistent identification of the broader population so as to ensure comparison with past and future research wherever possible. My purpose also included using the CIHR Team in Children's Pain database to assess and understand the current experiences of acute pain in Canadian children with a chronic illness.

Chronically ill children are a rapidly growing population with highly complex medical needs. The number of chronically ill children is growing primarily due to advancements in technology and advancing life expectancies in children with genetic malformations, syndromes, respiratory and gastrointestinal disorders and cancer. Chronically ill children are at higher risk of experiencing acute pain related to the considerable number of painful procedures carried out to aid in the diagnosis, maintenance and treatment of their illnesses [1,2, 20]. They are frequently subjected to numerous blood draws, IV starts, lumbar punctures, nasogastric tubes, catheter insertions dressing changes, along with multiple surgeries to improve their overall quality of life. These medical procedures may cause anxiety, fear and behavioral distress for children and their families, further intensifying their pain and potentially interfering with current or future care and development [3-7,9,10,12,13]. Several studies have consistently found that a significant proportion of hospitalized children receive inadequate pain management despite the vast increase in knowledge and treatment options related to acute pain in children [1,2,4]. Chronically ill children, when compared to acutely ill children, have been shown to require increased coordination of care. This is primarily due to involvement of numerous specialists, as well as an increased number of hospitalizations related to initial diagnosis and frequent exacerbations throughout their illness trajectories. As a direct result of these increased hospitalizations these children may be subjected to increased interventions, tests, medications and procedures, which can dramatically increase their exposure to acutely painful events [20,24, 38].

Numerous consensus guidelines have been created by organizations in response to the mounting evidence related to undertreated pediatric pain in an attempt to push the importance of children's rights to pain relief [14-19]. More importantly, many of these organizations state that "relief of pain should be a human right" and that failure to provide adequate pain control amounts to substandard and unethical care, leaving many to question the type and quality of care children in Canadian hospitals are currently receiving [1,7,8,16]. Thus when considering how to improve pediatric pain management in hospitalized children it is imperative that we look closely at acute pain in chronically ill children that they are at a higher risk than acutely ill children to experience acute pain during their hospitalizations, due to their increased care needs.

Therefore the purpose of this paper-based thesis was to critically review the literature on acute pain in hospitalized chronically ill children, as well as analyze, interpret and discuss the current practices in children's hospitals across Canada specific to acute pain in chronically ill children.

1. Background

1.1. Chronic Illness in Children

Chronic illness has become a major global health focus. The aim to prevent, delay and treat varying illnesses so as to decrease the severity of their chronic nature is a primary focus of the World Health Organization (WHO). The WHO estimates up to 70% of the world's deaths, and as high as 75% of the cost of health care, to be directly related to chronic illness (WHO). The number of chronically ill children varies widely depending on the definitions of chronic illness used, as well as the inclusion or exclusion of certain diagnoses within the definitions in research. There is ambiguous evidence on the incidence of chronic illness among children with estimates ranging from 5-31% of all children having a chronic illness [23, 24]. Much of the current research on chronic illness is disease specific; for example many researchers complete thorough investigations on illnesses they deem chronic, but do not allow enough transparency in their understanding of the definition of 'chronic illness' or criteria used to allow for comparisons with other diseases or illnesses [42,46-48]. Thus, for this study we utilized the medical conditions as listed by the WHO International Classification of Diseases (ICD) (http://apps.who.int/classifications/apps/icd/icd10online/), in combination with the Ontario Child Health Study (OCHS) classification of chronic illness in children, when discussing chronic illnesses (Appendix 3) [21,22]. As previously identified by many researchers this type of categorical approach does have its limitations, all of the disorders do not meet the criteria specified in the definitions of chronic illness or disease in children [21-24]. Thus the list of chronic illnesses included in the appendix has been modified from the original ICD list, to include only those disorders that meet diagnostic criteria and fit within the definition of pediatric chronic illness utilized within this thesis.

1.2. Acute Pain Experiences and their Detrimental Effects

There has been research on the experience of acute pain in the pediatric population in relation to both the short and long term effects, but the majority of this research has been completed using disease specific cases or pediatric patients in general [9-13,30,36]. Little research looks at the experience of acute pain in children with a chronic illness as a broad population. The research completed has aided in dispelling some of the myths related to pain in children, but more importantly it has encouraged the need for further investigation into the formulation and testing of assessment measures specific to the diverse characteristics of the pediatric population. More recently pediatric pain research has focused on treatments of pain in children specifically addressing the variety of painful procedures, experiences they endure, and the short and long term effects through out the child’s life. One of these areas is acute pain experienced by the hospitalized child and the effects these experiences can have on the future development of the child psychologically and physically, the development of the family, as well as their overall quality of life in relation to future hospitalizations and pain experiences [2-13, 35, 39-48, 50].

1.3. *Assessment of Acute Pain in Children*

There has been a greater focus on pediatric pain within health research since the late 1980’s leading to immense advances in the knowledge gained within this area. Initially this research focused on the physiological experience of pain in children, which led to increased refinement in assessments with a movement to include measurement tools specific for assessment of varying age groups, developmental levels and pain classifications (acute vs. chronic) [44,45,47,49]. There are three main approaches to pain measurement tools currently being utilized, self report, observational or behavioral, and physiological; each of which may play an integral role in adequate assessment of pain in pediatric patients [34]. Appropriate treatments for pain in children have also been a focus resulting in the identification of three main approaches to management of pediatric pain; physical, psychological and pharmacological (often referred to as the three P's [28,29,31-33]. These advancements in treatment options have also affected how treatment is provided, as well as when, how and what type of pain assessments are completed. Groups have also been established to guide investigators, when conducting research related to pediatric pain, to ensure reliable and valid outcomes that may be combined or compared to advance knowledge and understanding in a more cohesive nature [34-36].

Most recently research has been aimed at addressing the lack of effective management of a variety of acutely painful procedures and experiences described by specific groups of children [30]. Many researchers believe the key to encouraging better management is better assessment. This approach facilitates improved detection and monitoring of pain and decreases the chance that pain will be discounted or minimized in the clinical environment [1,26,27]. This emphasis has propelled researchers to look more closely at the new relationships and ideas found within the main categories involved in pediatric pain; that is, assessment, treatment and prevention, so as to ensure appropriate management.

1.4. Pediatric Pain Measurement Tools

Pediatric acute pain experiences involve the interaction of physiologic, psychological, behavioral, developmental, and situational factors. Pain is an inherently subjective, multifactorial experience, and as a result should be assessed and treated accordingly (www.ampainsoc.org/advocacy/pediatric2.htm). As previously mentioned, there are three main approaches to pain measurement tools currently being utilized, self report, observational or behavioral and physiological. Each of these has the potential to play an integral role in adequate assessment of pain in pediatric patients [34]. There are a variety of concerns when looking into the use or creation of standardized pain measurement tools within pediatrics. For example pediatrics encompasses numerous ages and differing developmental levels, there by making it very difficult to standardize any pain tool across the board. As a result numerous measurement tools have been created specific to age and/or developmental level, resulting in confusion and difficulty for researchers when trying to make direct comparisons between the scales themselves. Evidence demonstrates that validated measurement tools are being used as little as 58% of the time when assessing acute pain in children, this suggesting that almost half of pediatric acute pain measurement is not of a standardized nature [39]. Causing difficulty in comparisons within current literature, as well as leaving many to question the true prevalence of acute pain and the effectiveness of treatment options. Therefore many health organizations (Royal College of Nursing and International Association for the Study of Pain) are pushing for the creation and standardization of pain measurement tools specific to pediatrics, in an attempt to clarify current practices in a clear and concise manner. For example focusing on the validated pain measurement tools along with specific guidelines discussing their use, allows for interpretation of these measurement tools to be combined or compared in many different ways to increase our overall understanding of pediatric acute pain [2].

The Royal College of Nursing has a pain scales algorithm along with clinical practice guidelines, which discuss the majority of the pain measurement tools available as part of the three main approaches stated above [53]. This guideline also aids in educating health care professionals regarding specific usage of pain measurement tools, along with the specified age and cognition level the tool is validated for. In standardizing pain measurement the aim being that it will be easier to make comparisons within the literature to understand the true prevalence of pain in children in addition to identifying effective treatment options, there by advancing our ability to alleviate children's pain from an international and interdisciplinary perspective (http://childpain.org/).

Keeping in mind the current knowledge regarding the occurrence and detriment of pain in children, as well as the increased risk children with chronic illnesses have of experiencing pain, primarily acute pain while in hospital, it becomes clear that an area that requires more insight and understanding is the acutely painful experience of chronically ill children while in hospital.

2. Definition of Terms

2.1. Pain

"An unpleasant and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." **Acute pain** is pain that resolves quickly, lasting only until the noxious stimulus is removed or the underlying damage or pathology has healed, occasionally referring to pain lasting less than 6 months in duration at which point it is said to be chronic in nature. (www.iasp-pain.org).

2.2. **Chronic Illness**

Is an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. Chronic illness will certainly affect the person’s quality of life (www.chronicillness.org).

The following criteria are required for the definition of chronic conditions. These conditions: have a duration that has lasted, or is expected to last a minimum of 6 months, have a pattern of recurrence or deterioration, have a poor prognosis, produce consequences or sequelae that impact on the individual’s quality of life [51].

3. Research Layout

This thesis is paper-based and is broken down into two papers. The first paper (chapter 2) encompasses a discussion of the current literature in review of the thesis topics, directed towards a clinical audience. The second paper (chapter 3) is comprised of study results ensuing from a secondary analysis of existing data from the CIHR Team in Children's Pain research project 1 (Dr. Bonnie Stevens, Hospital for Sick Children, University of Toronto, Principal Investigator; Dr. Shannon Scott, Site Investigator for Stollery Children’s Hospital site), specifically utilizing data from the Canadian Pediatric Pain Research (CPPR) database, directed towards a pediatric academic journal.

3.1. Paper 1

3.1.1. Purpose

The purpose of the first paper was to examine, summarize and compare the literature focusing on chronically ill children's experiences while in hospital with acute pain and its associated measurement and assessment. This was completed by conducting an integrated review of the literature that was published in English and available on-line over the last 20 years. An integrative review summarizes past research and draws overall conclusions from the body of literature on a particular topic. A well-done integrative review meets the same standards as primary research in regard to clarity, rigor, and replication [52]. We utilized the resources available through the University of Alberta; specifically a research librarian specialized in health sciences research. These resources assisted us in developing comprehensive search strategies and key terms for this specific literature review.

3.1.2. Significance (paper 1)

This portion of the study provided a clear and concise review of the literature specifically related to acute pain in hospitalized children with chronic illness. This was completed through highlighting key findings within the literature, as well as discussing current agreement or discord in areas of focus.

3.1.3. Overall Research Question (paper 1)

What is known about acute pain in hospitalized chronically ill children, in the literature?

3.2. Paper 2

3.2.1. Purpose

The purpose of this portion of the study was to analyze and interpret current practices related to painful procedures (acute pain) inflicted upon chronically ill children in acute care environments. Specifically this study attempted to understand current practices, assessment measures and documentation tools used in relation to the pain experienced in response to a variety of painful procedures within this select population.

3.2.2. Significance (paper 2)

This paper demonstrated the current incidence and frequency of painful procedures in chronically ill children across eight tertiary pediatric hospitals in Canada, as well as provides description and insight into the current assessment practices of acute pain within this population. The findings from this work ultimately provide a snapshot of acute pain experienced by chronically ill children across Canadian Hospitals. The results of this study help provide a more detailed insight into appropriate areas for possible change and improvement related to chronically ill children and their pain experiences while in hospital.

3.2.3. Overall Research Question (paper 2)

What is the nature and frequency of painful procedures and pain assessments in children with chronic illness as assessed in eight Children's Hospitals across Canada?

3.2.4. Specific Research Questions

There are two facets to this research question

1) The nature and frequency of painful procedures, specifically "What is the frequency and type of painful procedures experienced by chronically ill children?"

And 2) The nature and incidence of pain assessments in children. “Out of the number of chronically ill children receiving pain assessments, what is the frequency of use between validated, and narrative, non-validated pain tool measures?”

Both of which will be uniquely specific to chronically ill children in acute care health settings.

4. Methods

4.1. Design

This study utilized an exploratory descriptive design to examine the frequency and nature of painful procedures and pain assessments in chronically ill children.

4.2. Sample and Canadian Pediatric Pain Research Database

In the development of the Canadian Pediatric Pain Research (CPPR) database, medical charts of 3840 children were reviewed by research nurses from 32 inpatient units within 8 Canadian pediatric hospitals. Data was extracted from the charts for the previous 24 hour period on the nature and frequency of painful procedures and pharmacological, physical and psychological pain management interventions. Using this CPPR database we explored the incidence and intensity of pain experienced by children with chronic illnesses. We utilized mixed methods to describe and compare the pain experiences by chronically ill children [52,55]. Previous research estimated a maximum of 31% of the pediatric population to have a chronic illness. We found 35.7% of the Canadian pediatric population to belong in this category resulting in a sample size of 1355 chronically ill children.

The WHO International Classification of Diseases (ICD), in combination with the Ontario Child Health Study (OCHS) classification of chronic illness in children, was narrowed utilizing the definitions specific to this thesis for chronic illness to create the Childhood Chronic Illness list (Appendix 1). The sample of chronically ill children obtained through the CIHR Team in Children's Pain CPPR database utilizing the primary and secondary diagnosis fields (fields 7and 8) (Appendix 2) was examined in order to isolate the children with a diagnosis present on the Childhood Chronic Illness list.

4.3. Data Analysis

For the second part of this study we conducted a secondary analysis using data collected as part of the CIHR Team in Children's Pain; the Canadian Pediatric Pain Research (CPPR) network database. Secondary analysis comes with advantages and disadvantages. A main advantage is that the data set is available therefore the data does not need to be collected. However this can also be a limitation as the data is received in an 'as is' state, thus no further information can be collected, or manner of collection changed.

Statistical analysis was performed using SPSS (version 19) [59]. Descriptive statistics included frequency distribution, measurements of central tendency and variance were utilized to examine; type and frequency of chronic diagnosis, age of children in the sample, frequency of painful procedures in children with chronic illness, and type of pain assessment tools documented in chronically ill children. Parametric statistics were used to compare the frequency of pain assessments and the frequency of use of validated and non-validated pain scales in chronically ill children across the eight hospitals. In addition t-test, and chi-square calculations were performed to further examine the relationships between the variables in the different groups.

The narrative documentation of pain assessments included in the data set consisted primarily of RN narrative documentation, which was converted into numerical responses for the purposes of analysis in this study. Adjusting these responses allowed us to be able to compare and contrast all types of pain assessments available within the database, both validated and non-validated.

4.4. Limitations

The study for paper 2 was based on secondary analysis of existing data. This data was limited by the manner in which it was collected, specifically chart extraction. The main limitations with chart extraction being, that only the previous 24 hours of each chart was used, there was no direct discussion involved with the professionals documenting in the chart, and if documentation was absent or incomplete in the chart no other sources of documentation were accessed. Also this section of the study was limited by the definitions specific to the CIHR Team in Children's Pain Project 1 Data Collection form, data codebook and operational definitions.

There has been limited research on acute pain experienced by children with chronic illness. Therefore, to facilitate valid comparisons across studies of the prevalence of acute pain in hospitalized children with chronic illnesses, international consensus about the conceptual definition of chronic health conditions in childhood [20-23] would be preferable. As a result of this lack of conceptual clarity, the findings emerging out of this thesis are limited in terms of comparability to other research due to variation in the understanding of chronic illness definitions and criterion used. However this thesis does provide a generalized population basis in relation to current review of the literature, as well as exploration and discussion regarding current practices across Canadian Children's Hospitals. This potentially allowing for increased ease of future comparisons through the provision of an accepted generalized conceptual definition of chronic illness in children.

5. Ethical Considerations

Ethics approval was sought through the Human Ethics Research Board – Panel B, at the University of Alberta prior to data analysis. In the initial data collection for the CPPR database no patient consent was required as chart extraction/abstraction was the sole means to acquire data. It is important to note that there was no new data collected for this thesis, rather secondary analysis of previously collected data by the CIHR Team in Children's Pain. A Data Transfer Agreement was put in place by the Hospital for Sick Children and the University of Alberta to transfer the anonymized data that was used for secondary analysis. Data sharing can make a valuable contribution to advancement of knowledge, with adequate attention to ethical considerations this can enhance the potential value public and private research agencies receive for their funding [56]. This data was then stored and analyzed within the University of Alberta – Faculty of Nursing Data Repository.

6. Nursing Significance

This program of work has clarified information on current acute pain practices in hospitalized children with chronic illness. It has potential to aid in facilitating health practitioner's pain research use by informing clinical, administrative and policy decision making. This is supported by the presence of Canadian specific content, in addition to allowing for eventual comparison to similar international data related to acute pain experiences in hospitalized children. Most importantly this study helps to promote improved quality of life in children with chronic illness experiencing acute pain by clearly stating current practices in Canadian pediatric hospitals; inviting potential further research and practice changes in the related areas.

The findings from this research identified current Canadian clinical practices related to identification and assessment of chronically ill children's acute pain while in a pediatric hospital. This study contributes to the overall knowledge and understanding of acute pain in chronically ill children, with the goal of potentially decreasing the overall mismanagement of pain in children.

References

[1]Taylor EM, Boyer K, Campbell FA. Pain in hospitalized children: a prospective cross-sectional survey of pain prevalence, intensity, assessment and management in a Canadian pediatric teaching hospital. Pain Res.Manag. 2008 Jan-Feb; 13(1): 25-32.

[2]Buscemi N, Vandermeer B, Curtis S. The Cochrane Library and Procedural Pain in Children: An Overview of Reviews. Evidence-Based Child Health: A Cochrane Review Journal 2008; 3:260-279.

[3]Uman LS, Chambers CT, McGrath PJ, Kisely S. A systematic review of randomized controlled trials examining psychological interventions for needle-related procedural pain and distress in children and adolescents: an abbreviated Cochrane review. J.Pediatr.Psychol. 2008 Sep; 33(8): 842-854.

[4]Stinson J, Yamada J, Dickson A, Lamba J, Stevens B. Review of systematic reviews on acute procedural pain in children in the hospital setting. Pain Res.Manag. 2008 Jan-Feb; 13(1): 51-57.

[5]Cummings EA, Reid GJ, Finley GA, McGrath PJ, Ritchie JA. Prevalence and source of pain in pediatric inpatients. Pain 1996 Nov; 68(1): 25-31.

[6]Ellis JA, O'Connor BV, Cappelli M, Goodman JT, Blouin R, Reid CW. Pain in hospitalized pediatric patients: how are we doing?. Clin.J.Pain 2002 Jul-Aug; 18(4): 262-269.

[7]Johnston CC, Abbott FV, Gray-Donald K, Jeans ME. A survey of pain in hospitalized patients aged 4-14 years. Clin.J.Pain 1992 Jun; 8(2): 154-163.

[8]Walco GA. Needle pain in children: contextual factors. Pediatrics 2008 Nov; 122 Suppl 3:S125-9.

[9]Kortesluoma RL, Nikkonen M. 'The most disgusting ever': children's pain descriptions and views of the purpose of pain. J.Child Health Care 2006 Sep; 10(3): 213-227.

[10] Kortesluoma RL, Nikkonen M. 'I had this horrible pain': the sources and causes of pain experiences in 4- to 11-year-old hospitalized children. J.Child Health Care 2004 Sep; 8(3): 210-231.

[11] Von Baeyer CL, Marche TA, Rocha EM, Salmon K. Children's memory for pain: overview and implications for practice. J.Pain 2004 Jun; 5(5): 241-249.

[12] Humphrey GB, Boon CM, van Linden van den Heuvell GF, van de Wiel HB. The occurrence of high levels of acute behavioral distress in children and adolescents undergoing routine venipunctures. Pediatrics 1992 Jul; 90(1 Pt 1): 87-91.

[13] Hamilton JG. Needle phobia: a neglected diagnosis. J.Fam.Pract. 1995 Aug; 41(2): 169-175.

[14] International Association for the Study of Pain. IASP Pain Terminology. Available at: http://www.iasp-pain.org/AM/Template.cfm?Section=Pain_Definitions. Accessed 07/15, 2010.

[15] World Health Organization, International Association for the Study of Pain. Cancer pain relief and palliative care in children. 1998.

[16] American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health, Task Force on Pain in Infants, Children, and Adolescents. The assessment and management of acute pain in infants, children, and adolescents. Pediatrics 2001 Sep; 108(3): 793-797.

[17] Anand KJ, International Evidence-Based Group for Neonatal Pain. Consensus statement for the prevention and management of pain in the newborn. Arch.Pediatr.Adolesc.Med. 2001 Feb; 155(2): 173-180.

[18] Watt-Watson JH, Clark AJ, Finley A, Watson CP. Canadian Pain Society position statement on pain relief. Pain Res Manage 1999; 4(2): 75-78.

[19] Phillips DM. JCAHO pain management standards are unveiled. Joint Commission on Accreditation of Healthcare Organizations. JAMA 2000; 284:428-429.

[20] Stille CJ, Primack WA, Savageau JA. Generalist-Subspecialist Communication for Children with Chronic Conditions: A Regional Physician Survey. Pediatrics. 2003 Dec; 112(6): 1314-1320.

[21] Davis MM, Brosco JP. Being Specific About Being Special: Defining Children’s Conditions and Special Health Care Needs. Arch Pediatr Adolesc Med. 2007 Oct; 161(10): 1003-1005.

[22] Van der Lee JH, Mokkink LB, Grootenhuis MA. Definitions and Measurement of Chronic Health Conditions in Childhood: A Systematic Review. JAMA 2007; 297(24): 2741-2751

[23] Perrin JM, Bloom SR, Gortmaker SL. The Increase of Childhood Chronic Conditions in the United States. JAMA 2007: 297(24): 2755-2759.

[24] Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. An Epidemiologic Profile of Children With Special Health Care Needs. Pediatrics 1998; 102(1): 117-123.

[25] Walco GA, Cassidy RC, Schechter NL. Pain, Hurt, and Harm – The Ethics of Pain Control in Infants and Children. New England Journal of Medicine 1994 Aug; 331(8): 541-544.

[26] Breau LM. Assessing Pain in Children with Intellectual Disability. Journal of Pain Management 2009: 2(1): 11-21.

[27] Breau LM, Finley GA, McGrath PJ, Camfield C. Validation of the Non-Communicating Children's Pain Checklist – Postoperative Version. Anesthesiology 2000; 96: 528.

[28] Cohen LL. Behavioral approaches to anxiety and pain management for pediatric venous access. Pediatrics 2008; 122(supplemental): S134. doi:10.1542/peds.2008-1055f

[29] Cohen LL, Lemanek K, Blout RL, Dahlquist LM, Lim CS, Palermo T, McKenna KD, Weiss KE. Evidence - based assessment of pediatric pain. Journal of Pediatric Psychology 2008; 33(9): 939.

[30] Kennedy RM, Luhmann J, Zempsky WT. Clinical implications of unmanaged needle-insertion pain and distress in children. Pediatrics 2008; 122: S130-3.

[31] Schechter NL. From the ouchless place to comfort central: The evolution of a concept. Pediatrics 2008; 122: S154-60.

[32] Zempsky WT. Optimizing the management of peripheral venous access pain in children: Evidence, impact, and implementation. Pediatrics 2008; 122: S121-4.

[33] Zempsky WT. Pharmacologic approaches for reducing venous access pain in children. Pediatrics 2008; 122: S140-53.

[34] von Baeyer CL, Spagrud LJ. Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. Pain 2007; 127(1-2): 140-150.

[35] Brennan-Hunter AL. Children's pain: A mandate for change. Pain Research Management 2001: 6(1): 29.

[36] Gibbins S, Stevens B, McGrath PJ, Dupuis A, Yamada J, Beyene J, Breau LM, Camfield C, Finley GA, Franck L, Johnston C, McKeever P, O'Brian K, Ohlsson A. Changes in physiological and behavioral pain indicators over time in preterm and term infants at risk for neurological impairment. Early Human Development 2008; 84: 731.

[37] Helms JE, Barone CP. Physiology and treatment of pain. Critical Care Nurse 2008; 28(6): 38.

[38] Dosa NP, Boeing NM, Kanter RK. Excess Risk of Severe Acute Illness in Children with Chronic Health Conditions. Pediatrics 2001; 107(3): 499.

[39] Barden J, Edwards JE, Mason L, McQuay HJ, Moore RA. Outcomes in acute pain trials: Systematic review of what was reported. Pain 2004; 109: 351.

[40] Benini F, Trapanotto M, Gobber D, Agosto C, Carli G, Drigo P, Eland J, Zacchello F. Evaluating pain induced by venipuncture in pediatric patients with developmental delay. Clinical Journal of Pain 2004; 20(3): 156.

[41] Cummings EA, Reid GJ, Finley GA, McGrath PJ, Ritchie JA. Prevalence and source of pain in pediatric inpatients. Pain 1996; 68: 25.

[42] Jakubik LD, Thompson M. Care of the child with sickle cell disease: Acute complications. Pediatric Nursing 2000; 26(4): 373.

[43] Leahy S, Kennedy RM, Hesselgrave J, Gurwitch K, Barkey M., Millar TF. On the front lines: Lessons learned in implementing multidisciplinary peripheral venous access pain-management programs in pediatric hospitals. Pediatrics 2008; 122: S161-70.

[44] McGrath PA, Speechly KN, Seifert CE, Biehn JT, Cairney AEL, Gorodzinsky FP, Dickie GL, Morrissy JR. A survey of children's acute, recurrent and chronic pain: Validation of the pain experience interview. Pain 2000; 87: 59.

[45] McGrath PJ, Walco GA, Turk DC, Dworkin RH, Brown MT, Davidson K, Eccleston C, Finley GA, Goldschneider K, Haverkos L, Hertz SH, Ljungman G, Palermo T, Rappaport BA, Rhodes T, Schechter N, Scott J, Sethna N, Svensson OK, Stinson J, von Baeyer C, Walker L, Weisman S, White RE, Zajicek A, Zeltzer L. Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. Journal of Pain 2008; 9(9): 771-783.

[46] Mercadante S. Cancer pain management in children. Palliative Medicine 2004; 18(7): 654-662.

[47] Miaskowski C, Nichols R, Brody R, Synold T. Assessment of patient satisfaction utilizing the American pain society's quality assurance standards on acute and cancer-related pain. Journal of Pain & Symptom Management 1994: 9(1): 5-11.

[48] Powers DM. Ratings of pain from postoperative children and their nurses. Nursing Papers 1987; 19(4): 49.

[49] Simon JM, Baumann MA, Nolan L. Differential diagnostic validation: Acute and chronic pain. Nursing Diagnosis 1995; 6(2): 73-79.

[50] Taddio A, Chambers CT, Halperin SA, Ipp M, Lockett D, Rieder MJ, Shah V. Inadequate pain management during routine childhood immunizations: The nerve of it. Clinical Therapeutics 2009; 31(Supplement B): S152.

[51] O'Halloran J, Miller GC, Britt H. Defining Chronic Conditions for Primary Care with ICPC – 2. Family Practice 2004; 21:381-386.

[52] Byea S, Nichll LH. Writing an Integrative Review. AORN Journal, April, 1998.

[53] Stemler S. An Overview of Content Analysis. Practical Assessment, Research and Evaluation 2001; 7(17): 1-10.

[54] Royal College of Nursing. Clinical Practice Guidelines: The recognition and assessment of acute pain in children, September 2009. Available at: http://www.rcn.org.uk/development/practice/pain/downloads. Accessed 07/21/2010.

[55] Hsiu-Fang H, Shannon SE. Three Approaches to Qualitative Content Analysis. Qualitative Health Research, November 2005: 15(9): 1277-1288.

[56] Morse JM, Field PA. Qualitative Research Methods for Health Professionals, 2nd ed. 1995. SAGE Publications: Thousand Oaks, CA.

[57] Cobban SJ, Edgington EM, Pimlott JFL. An Ethical Perspective on Research Using Shared Data. Can J Dent Hygiene 2008; 42(5): 233-238.

[58] Doolan DM, Froelicher ES. Using an Existing Data Set to Answer New Research Questions: A Methodological Review. Research & Theory for Nursing Practice 2009; 23(3): 203-215.

[59] Howitt D, Cramer D. Introduction to SPSS statistics in psychology: For version 19 and earlier. 5th revised edition, March 2011. Pearson Custom Publishing.

Chapter 2: Acute Pain in Hospitalized Chronically Ill Children: A Critical Review

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The first author (Medynski) received funding from the Canadian Institute of Health Research (CIHR) Team in Children's Pain – Master's Scholarship for related research. The senior author (Scott) receives research personnel funding from the Alberta Heritage Foundation for Medical Research and the Canadian Institutes of Health Research.

Acknowledgment. We would like to acknowledge Dr. Dawn Davies for her contributions to previous drafts of this manuscript.

Acute Pain in Hospitalized Chronically Ill Children:
A Critical Review

1.Introduction

Chronically ill children are a rapidly growing population with highly complex medical needs. The number of chronically ill children is growing primarily due to advancements in technology and advancing life expectancies in children with genetic malformations, syndromes, respiratory and gastrointestinal disorders and cancer. Chronically ill children are at higher risk of experiencing acute pain related to the considerable number of painful procedures carried out to aid in the diagnosis, maintenance and treatment of their illnesses [1-5]. They are frequently subjected to numerous blood draws, IV starts, lumbar punctures, nasogastric tubes, catheter insertions, dressing changes, along with multiple surgeries to improve their overall quality of life.

These medical procedures may cause anxiety, fear and behavioral distress for children and their families, further intensifying their pain and potentially interfering with current or future care and development [6-11]. Several studies have consistently found that a significant proportion of hospitalized children receive inadequate pain management despite the vast increase in knowledge and treatment options related to acute pain in children [1,4,12,13,39]. When compared to acutely ill children, chronically ill children have been shown to require more coordination of care. Primarily due to the involvement of numerous specialists, an increased number of hospitalizations related to initial diagnosis and frequent exacerbations throughout their illness trajectories. As a direct result of these increased hospitalizations these children may be subjected to increased interventions, tests, medications and procedures, which can dramatically increase their exposure to acutely painful events [3,14-15, 40]. Many researchers believe the key to encouraging better pain management is better assessment. This premise then facilitates improved detection and monitoring of pain, decreases the chance that pain will be discounted or minimized in the clinical environment [4,16]. This work has prompted researchers to look more closely at new relationships and ideas found within key categories involved in pediatric pain; assessment, treatment and prevention, so as to ensure appropriate management.

Over the past few years there has been a push to standardize pain measurement resulting in numerous attempts to validate pain tools. The aim of standardization of pain tools is to improve the ability to make comparisons within the literature, to allow for better understanding of the true prevalence of pain in children, in addition to identifying effective treatment options, there by advancing our ability to alleviate children's pain from an international and interdisciplinary perspective [17, 41]. If the research focus remains on individual diagnosis, studied during restricted or narrowed time periods, with numerous elimination variables, overall comparisons between studies are difficult if not impossible to make. This ultimately hinders advanced understanding of acute pain in children due to the lack of understanding of pain generally at a population level. Examining acute pain in children using similar standards, language, and tools would allow ease comparisons between studies, and potentially advance understanding of acute pain in children with chronic illness as a distinct population within the pediatric population.

Numerous consensus guidelines have been created by organizations in response to the mounting evidence of undertreated pediatric pain in an attempt to advance the importance of children’s rights to pain relief [18-23]. More importantly, many of these organizations state that “relief of pain should be a human right”, and failure to provide adequate pain management amounts to substandard and unethical care, leaving many to question the quality of this aspect of care, particularly for hospitalized children [4,10,12,18,24,25]. This issue is even more important when considering how to improve pediatric pain management in children with cognitive impairment, because they are potentially at a higher risk than acutely ill children to experience acute pain during their hospitalizations, related to their increased care needs. This is clearly an area that requires more insight and research.

2. Methods

The purpose of this paper is to examine, summarize and critically assess the literature focusing on the experiences of hospitalized chronically ill children with acute pain, and its associated measurement and assessment. Authors JM and SS conducted a critical review of the literature published in English and available on-line from the previous 20 years. Given the limited literature on this topic, a systematic review could not be completed. We augmented the systematic review approach to be able to systematically get a snapshot of the literature on this topic. Specifically we used a rigourous, systematic approach to aquire the literature, including all available studies (research, case studies, dissertation and thesis, etc).

2.1. Procedures

The search strategy for this literature review was guided by the purpose to identify current existing evidence related to acute pain experienced by chronically ill children, while in the hospital setting. An electronic search of the following six bibliographical databases was performed: CINAHL, MEDLINE, PubMed, Scopus, Nursing & Allied Health Source, and Health Source: Nursing /Academic Edition. Literature published in English between the dates of January 1990 and September 2010 was assessed for inclusion. Search terms were key words: pediatric or paediatric or child or children; acute pain; chronic illness or chronic disease or chronic condition. A research librarian was utilized during the preliminary inclusion criteria to ensure proper search techniques were used between databases, thereby ensuring similar searches were carried out.

2.2. Inclusion Criteria

No exclusions were made regarding research design of the articles included. The search strategy identified 525 manuscripts for screening. A primary screening was completed through assessment of the manuscript title and abstract (if available), resulting in 57 articles for secondary screening. These articles underwent a final inclusion review, which consisted of a thorough analysis of the article for content specifically related to chronically ill children, with a focus on children in hospital settings, as well as discussion of acute pain as a prominent topic. Due to a lack of consensus on a commonly agreed upon definition of chronic illness, a generalized definition along with a list of criteria were utilized in the screening process to identify chronic illnesses, conditions and/or diseases in children. The generalized definition was; ‘Chronic illness is an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. Chronic illness will certainly affect the person’s quality of life’ (www.chronicillness.org.au). The following criteria are required for the definition of chronic conditions. These conditions may; have a duration that has lasted, or is expected to last at least 6 months, have a pattern of recurrence or deterioration, have a poor prognosis, produce consequences or sequelae that impact on the individual’s quality of life [26].

The articles did not need to be original research to be included, because these are of a limited number. We were looking for current evidence of all levels, and discussion on the specified topic (Table 1). A total of nine studies were available for inclusion (Table 2).

The retrieved articles were then sorted by design and fell into three broad categories; experimental, quality improvement, and opinion (Table 3). Experimental articles were conceptualized for the project as having an underlying goal to test theory through the manipulation of an independent variable. Quality improvement (management) articles were identified as an evaluation of services (care) provided and discussion of the results or findings in relation to acceptable standards [27]. Opinion articles were conceptualized as a publication expressing the opinions of the writer, which may or may not be substantiated with facts. The findings are grouped and presented by study type.

3. Results

Of the nine manuscripts, 4 were experimental, 2 were quality improvement; and 3 were opinion articles. The four categorized as experimental were (16, 28-30]. The two categorized as quality improvement articles were [31,32]. The three remaining articles were categorized as opinion based on their overall content [33-35]. The articles arose from a variety of countries, Canada (n=3), the United States (n=3), the United Kingdom (n=1), Italy (n=1), and the Netherlands (n=1), but the majority of articles discussed here were North American. Unfortunately we were unable to methodically interpret the literature statistically given its diversity. The literature consisted of various differing formats, experimental, quality improvement and opinion. Resulting in varied discussions pertaining to original data, statistical analysis, independent results, as well as secondary analysis, and current practices and beliefs.

We assessed the articles from their definitions of pain or acute pain. Other areas of focus explored within the articles are highlighted within Table 3. In addition, we explored in further depth the myths and beliefs about pain in chronically ill children, and the findings and conclusions of each article. Articles varied in how they identified chronically ill children, as well as how they perceived the education, knowledge and understanding, and actions of health care professionals related to practices related to acute pain in hospitalized chronically ill children. In the articles there was a vast array of concerns surrounding opioid use and its related risks. As well, some discussed subsequent responses to pain and fear of chronically ill children, their families and the health care professionals who care for them while in hospital. These are further highlighted in Table 4, and explained in more depth.

3.1. Definitions of Pain or Acute Pain

Meredith (1999) was the only author included in this literature review to specify a definition for both pain and acute pain. Her definition of pain was the International Association for the Study of Pain (IASP) definition from 1979: “ Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” [20,36]. Meredith’s definition of acute pain was stated to be “pain which occurs as an automatic response to noxious stimulus”. None of the authors of the opinion articles included clear definitions for pain or acute pain. The two articles by Kennedy, 2008 and Mercadante, 2004, allude to acute pain and procedural pain as being synonymous but do not explicitly state this [34,35].

3.2. Experimental

The experimental studies were published between 1999 and 2003, two originated in Canada (Breau, 2002 and Meredith, 1999); one in the United States (Jacobs, 2002) and the final from the Netherlands (Terstegen, 2003). Breau looked specifically at validation of the non-communicating children’s pain checklist to ensure the clinical utility of the tool by assessing child’s pain by an unfamiliar adult. Breau completed her study using children ages 3-19 years (N=24) with profound cognitive impairment (PCI) experiencing acute surgical (post-operative) pain. She found the suggested properties of the pain scale good in identifying postoperative pain in children with severe intellectual disabilities when utilized by non-familiar providers. Terstegen, similar to Breau, looked at acute post-operative (surgical) pain in hospitalized children ages 3-19 years (N=52), but specifically defined children with profound cognitive impairment “as having a cognitive development estimate to be below a chronological age of 2 years, or IQ equivalent to 0-20" [30]. In this study, exclusion criteria were: 1) recent change in living environment less than one month prior to the study, 2) abnormal renal, adrenal or liver function, 3) patient younger than 2 years of age. This resulted in a study sample including a variety of chronic conditions ranging from chromosomal, metabolic or congenital abnormalities to cerebral palsy, anemia, asthma and gastro esophageal reflux. Terstegen's aim was to identify possible indicators of post surgical pain in children with PCI, which were observable in a clinical setting, and identifiable by persons not familiar with the patient. Terstegen's study identified a core set of indicators for assessing post surgical pain in children with profound cognitive impairment. There were similarities in the defined study populations in the Terstegen and Breau studies. Their aim to identify tools for pain assessment and measurement, for use by persons not directly familiar with the patient, was also similar, and both studies reported (or suggested) that their findings were potentially useful in a clinical environment.

Jacobs studied intermittent acute pain in children with sickle cell disease, specifically vaso-occlusive pain related to its changes in intensity, location and quality. Inclusion criteria were 1) pain directly related to a vaso-occlusive episode, 2) no prior history of neurological impairment 3) no visual or hearing deficits, 4) no motor function deficits and/or developmental delay. Jacobs' study population was 27 English-speaking children, ages 5-19. Like Jacobs, Meredith studied hospitalized children with sickle cell disease, but unlike Jacobs she did not look at current responses to pain related to vaso-occlusive episodes. She evaluated children who have experienced recurrent episodic pain (sickle cell related vaso-occlusive episodes in the past), and compared them to children who have not experienced recurrent pain. Meredith examined her study population to determine the relationship between the number of hospitalizations and the number of experiences with needles (inflicted finger sticks), to the overall effect on the impact of pain intensity and medical fears. Children in Meredith's study were included if they were 1) not currently experiencing an acutely painful episode (opposite to Jacobs study), 2) were able to use the identified pain scales, 3) did not have any other chronic illnesses, and 4) had experienced a minimum of one painful vaso-occlusive episode within the last year, or a minimum of 10 in their lifetime. This resulted in a study population of 66 children (33 with sickle cell disease, and 33 matched children without sickle cell disease; matched by age, sex, and ethnic origin). Children were either English or French speaking, between the ages of 7-12 years. Therefore, even though Jacobs and Meredith both studied the specific population of similarly aged hospitalized children with sickle cell disease, they looked at two very different time periods related to the pain experience within this population, aimed at two very different areas of examination.

3.3. Quality Improvement

Both authors in this category evaluated care actually provided in relation to acceptable standards, though their approach is methodologically different. For example, Rivard explored the attitudes, knowledge and practices of hospital- based nurses with regard to acute pain in hospitalized children. Charlesworth predominantly looked at health care professionals' acknowledgment of pain in relation to seizures. As generalized as Rivard is in regards to children with chronic disabilities, Charlesworth is specific in his discussion on paroxysmal focal pain with seizures. Despite these vast differences in focus and style, both authors call attention to pain being initially recognized in order to be properly assessed and managed as a priority, regardless of the underlying disorder. Charlesworth wrote about a specific case of a 17-year- old female experiencing acute epileptic pain lasting 10-30 seconds and occurring 1-2 times per day since the age of three years. He further discussed the idea of painful seizures or pain with the tonic muscular contractions during seizures, as well as discussion of previous research related to painful seizures, concluding that the identification of pain as an epileptic manifestation will allow for the appropriate selection of treatments. Rivard’s article on acute postoperative pain control in children with chronic disabilities is categorized as a quality improvement article due to its combination of opinion of current care practices and discussion of previous research completed in the USA. The previously conducted research was done in the early 1990’s by the author, in direct relation to the Gillette Children’s Specialty Healthcare team’s management of multiple lower extremity procedures (MLEPs). This article included lists of discussion topics specific to pain management for the nurse in order to optimize pain control, as well as key areas on which to focus during patient and family education prior to discharge home. This author concluded that pain management programs should include his identified criteria in order to be effective.

3.4. Opinion

Two opinion articles (e.g. Kennedy, 2008; Mercadante, 2004) which fit the requirements for inclusion into this review, focused on acute pain related to procedural pain specific to children with cancer [34,35]. These two articles were similar in their focus for discussion of the reasons for the under treatment of pain in children. Mercadante explored the causal factors, while Kennedy focused on the need for increased pain management. Both discussed long-term consequences of undertreated and untreated pain in children. These include exaggerated memories, negative memories, avoidance of health care, denial of pain, increased analgesic requirements, and increased anxiety and fear in the children, their families and the care provider. Kennedy described the effect of unmanaged pain on health care providers as increased patient physical restraint or injury, decreased morale, increased stress and increased time necessary to provide adequate care and treatment due to increased fear and anxiety of the patient and/or family. Mercadante expanded upon both families and health care providers inexperience and unfounded fears leading to reluctance to use appropriate potent analgesics. Through the combination of these two articles it becomes clearer the full impact unmanaged pain in children can have on everyone involved. One article (Friedrichsdorf, 2007) was much broader in its discussion of chronic illness in children, providing a distinct four-group classification system for children with life-limiting conditions, including examples for each. These classifications have aided in the increased generalizability of the discussions within this article to a greater population, in contrast to the three other opinion articles.

Of all of the articles included within this integrative review, the most recently published article (Charlesworth, 2009) is also the most specific in its defined population. In contrast, earlier articles evaluated the more generalized populations (Breau, 2002; Friedrichsdorf, 2007; Rivard, 2001; and Terstegen, 2003). This caused us to question if we are generating new knowledge of children in pain, or only advancing our understanding of children with acute pain in very specialized circumstances, which might not be applicable to other children within the chronic illness population.

3.5. Myths, Beliefs and Findings

When analyzing the articles as a whole, their findings reflect ongoing existence of poorly managed pain in chronically ill children. To note which articles discussed myths, the authors' beliefs or the study findings, please refer to Table 4.

3.5.1. Differences in chronically ill children.

All of the articles commented on the differences in children with chronic illness and the impact this had on their basic needs. For example, Breau felt there was a lack of available and validated pain assessment tools for this population, whereas Terstegen believed communication difficulties in a similar population of chronically ill children was the main reason for poor acute pain management. Rivard stated that pain management in children with chronic illness is different from pain management in children with acute injury or illness, related to their increased care needs, physical conditions and emotional states. Meredith extensively discussed many myths surrounding children with chronic illness, specifically sickle cell disease. She, too, speculated that lack of knowledge and understanding of acute pain in chronically ill children by health care professionals is the main reason for ongoing inadequately managed pain. She also discussed the presence of mistrust, both on the part of the health care provider who views the patient as drug dependent, difficult or manipulative. In addition to the parents, who may mistrust health care professional's to manage their child's pain. This bidirectional doubt increases the difficulty that the patient experiences accessing medications, or receiving appropriate assessments and treatments. Meredith concluded that increased hospitalizations in this population results in decreased sensitivity to acute pain and an overall decrease in medical fears (scores resulting in $p < .01$).

3.5.2. Lack of education, understanding or action of health care professionals.

In the experimental article by Jacob, there is a concentration of beliefs from previous research that points to a failure on the part of the clinician or health care professional as the main reason for poor pain management in chronically ill children. Jacobs comments on the state of this knowledge and bias resulting in failure linked to clinicians' lack of ongoing pain assessments and evaluations specific to the effectiveness of the analgesic regimen. She also comments on the health care professionals (clinicians) inappropriate use of patient controlled analgesia (PCA) devices as well as their inappropriate titration of opioid analgesics. Rivard also presents the belief that poor nursing education in assessment and treatment measurements specific to childhood acute pain is responsible for ongoing inadequacies in pain management in hospitals. In Mercandante's opinion, the inexperience and poor understanding of health care providers and families regarding current knowledge, innovative techniques, basic pharmacokinetics and potent analgesics is a primary reason for this problem.

3.5.3. High risk of opioid use.

Despite numerous studies supporting the safety of opioid use for children with moderate to severe pain, many of the authors commented on the persistence of negative beliefs surrounding opioid use. For example Rivard, Friedrichsdorf and Mercadante all commented on the belief, held both by families and health care professionals, that is an increased risk of respiratory depression and potential to hasten death as a primary reason for poor pain control in chronically ill children. Friedrichsdorf and Mercadante go further to comment on the propagation of unfounded or inappropriate concerns related to opioid addiction as a limitation to their appropriate use.

3.5.4. Response to subsequent pain and fears.

In the opinion article by Kennedy, there is extensive discussion of his beliefs and previous research findings that unmanaged pain leads to a variety of long-term consequences, specifically altered pain sensation. He discusses how the memory of pain can subsequently increase future reactions to pain if poorly or inadequately managed, specifically through exaggerated memories heightening stress levels and anxiety, as well as increased need for analgesics. Within Kennedy's discussion of these beliefs, he cites previous research that supports this conclusion. The experimental article by Meredith, in contrast to Kennedy's, commented on the potential for unmanaged pain to alter future pain experiences, but discussed findings contradicting Kennedy's. Meredith's research found that increased hospitalizations in children with sickle cell disease resulted in less sensitivity to acute pain and an overall decrease in medical fears or anxiety. In comparing these articles, it is pertinent to note that Meredith based her comments on 1999 research which had a sample size of N = 66. This study was located within 'grey literature' and was unable to be located within a peer reviewed published journal. Kennedy's article, though opinion based, discussed numerous recently published research findings from 1987 to 2008.

4. Discussion

4.1. Implications for Future Research and Practice

The findings of our review suggest that much of the current research on pain in chronic illness is disease specific, or extensively limited in study inclusion criteria. This limits the generalizability of the findings, as ‘chronic illness’ in children is as an all-encompassing term. This specificity and changing criteria contributes to why there is a large discrepancy in the overall estimates of chronic illness in children ranging from 5-31% [37,38]. The research completed as well as the literature written on pediatric acute pain has aided in dispelling some of the myths related to pain in children, but more importantly, it has identified areas of further need for research and investigation. This includes the formulation and testing of assessment measures validated tools specific to the diverse characteristics of this pediatric population. These need to be specific enough for use by children with a variety of age and developmental levels, but general enough to be used for differing pain categories (acute vs. procedural). As previously stated, many researchers believe the key to encouraging better management is better assessment. This premise then facilitates improved detection and monitoring of pain, and decreases the chance that pain will be discounted or minimized in the clinical environment. By reviewing current literature on acute pain in hospitalized chronically ill children, researchers and clinicians are encouraged to examine further possible better ways of identifying, assessing and managing pediatric pain. The ultimate goal is to create new or improved methods of decreasing the short and long-term detrimental effects of pain on an ever-growing population, chronically ill children.

As previously stated, there are many barriers to using or creating standardized pain measurement tools within pediatrics. Differing patient ages, developmental levels, and linguistic ability to describe their perceptions of acute or chronic pain confound such tools. This results in confusion not only for researchers but clinicians as well; leaving unanswered the question as to the true prevalence of acute pain, and the effectiveness of current treatment options and practices. Despite these difficulties, many international pain associations state that the drive to create appropriate standardized pain measurement tools is the best way to attempt to clarify current practices in a clear and concise manner, which would also allow for further comparison between studies (e.g. American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health, Task Force on Pain in Infants, Children and adolescents and International Association for the Study of Pain (IASP).

The findings from this literature review identify current international clinical practices and thoughts related to the identification and assessment of hospitalized chronically ill children experiencing acute pain. This contributes to the overall knowledge and understanding of acute pain in chronically ill children, with the potential of decreasing the overall mismanagement of pain in children, by identifying necessary next-steps for further studies.

5. Conclusion

Chronically ill children are at increased risk of hospitalization, and these hospitalizations place an amplified potential for children to be subjected to painful interventions, tests, and procedures. With the number of chronically ill children rapidly growing, and their potential to be at increased risk for experiencing acute pain while in hospital, it is important to have a clear understanding of the current situation, and to improve it. There are many myths and barriers facing practitioners and families when identifying, assessing or managing pain in this complex group of children. In an attempt to synthesize the existing literature, it becomes apparent that differing inclusion/ exclusion criteria and differing diseases or illnesses of focus, make it challenging to generalize findings.

5.1. Nursing Practice Implications

Chronically ill children are a vastly diverse and expanding population frequently seen in hospital. They recurrently experience numerous acutely painful interventions for which they often receive minimal to no pain assessment or management. A primary step in applying this evidence is awareness that hospitalized children are often inadequately treated for pain. The next step is acknowledging that children with chronic illness may be at greater risk to experience pain while in hospital. This knowledge may increase vigilance for nurses working with these hospitalized patients to be very conscious of the need for ongoing pain assessment and timely prevention or treatment.

There are many reasons cited for inadequate pain management in hospitalized children reviewed within this article. Acknowledgement and understanding of the potential negative effect on the chronically ill child’s hospital experience is the first step to put this evidence into practice. By acknowledging this populations’ elevated risk for unmanaged pain, nurses are increasing their potential to act and improve in the detection and management of pain.

The second suggestion implied by this evidence is for nurses to increase their knowledge and understanding of pain, and to understand the role that their biases may play in diminishing overall pain management. This includes learning the keys of assessment and management techniques proven to be effective for children. This education could be delivered through informational emails, in-services, informal/formal discussions, adjustments to documentation tools and practices, conferences, and journal groups. Increased knowledge in the area would aid in building confidence around making appropriate clinical decisions related to pain assessment and management, as well as aid to build trust and decrease fears and misconceptions, both for the nurse, the patient and their families.

Table 2.1. Article Exclusion Criteria

The main reasons articles were not included in the final data set were:
• No indicators of a hospitalized environment • No indicators of pediatric specific content • No specification between acute and chronic pain • No identification of acute or chronic illness • Published prior to January 1990, or after September 2010. • Not published in English

Table 2.2. Search and Retrieval Process for Articles

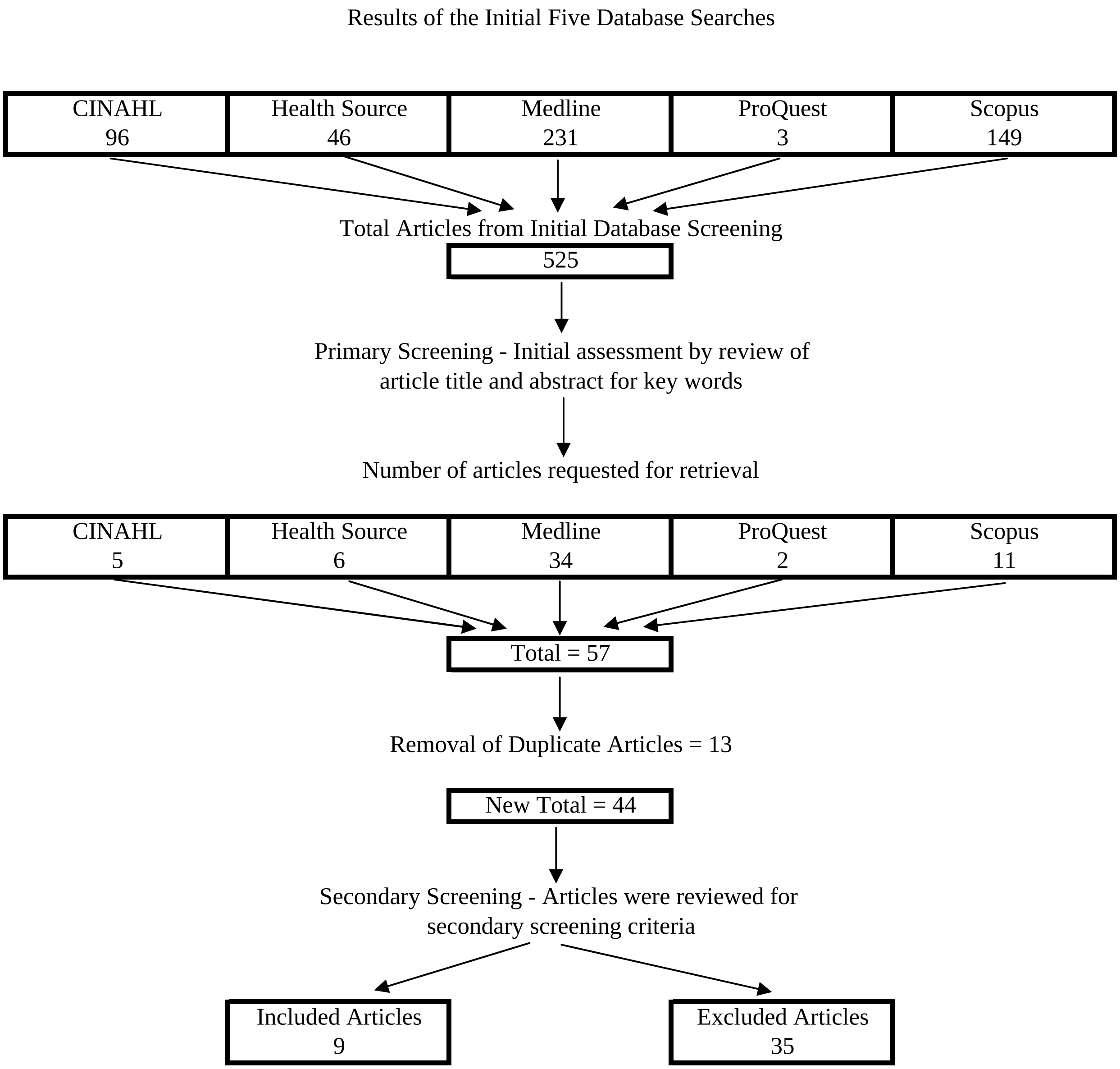

Table 2.3. Charateristics of Included Studies

Authors(s), Year, Country	Journal	Type of Article (opinion, research experiment)	Key Topics Present in Article from Primary and Secondary Screening	Pain Definitions Utilized within the Article	Other Areas of Focus Explored within the Article
Breau L, Finley A, McGrath P, Camfield C, 2002, Canada	Anesthesiology	experiment	acute surgical pain, chronic illness, hospitalized	no definition for pain or acute pain	Non-communicating Children's Pain Checklist - Postoperative Version (NCCPC-PV), profound intellectual delay, 3-19 yrs, N=24,
Jacob E, Miaskowski C, Savedra M, Beyer J, Treadwell M, Styles L. , 2002, USA	Pain	experiment	intermittent pain, acute care admission, children, sickle cell disease	no definition for pain or acute pain	vaso-occlusive pain, no history of neurological impairment, 5-19 yrs, N=27, single hospital in California, Pain intensity, location and quality,
Meredith P, 1999, Canada	Dissertation & Thesis	experiment	acute pain, sickle cell disease, hospitalization, children	**Pain -** "is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (IASP, 1979)" **Acute Pain -** pain which occurs as an automatic response to noxious stimulus	healthy children, adaptation of the pain response, Colored Analogue Scale, Child Medical Fears Scale, N=66, 7-12 years,
Terstegen C, Koot H, deBoer J, Tibboel D, 2003, Netherlands	Pain	experiment	acute post-operative pain, hospitalized, children, chronic illness	no definition for pain or acute pain	profound cognitive impairment, increased risk of pain, increased pain tolerance, single hospital, required normal renal, adrenal and liver function for inclusion, N=52, visual analog scale,

Table 2.3. Characteristics of Included Studies

Author(s), Year, Country	Journal	Type of Article (opinion/research experiment)	Key Topics Present in Article from Primary and Secondary Screening	Pain Definitions Utilized within the Article	Other Areas of Focus Explored within the Article
Charlesworth G, Soryal I, Smith S, Sisodiya S., 2008, UK	Pain	quality improvement	acute pain, child, hospitalized, epilepsy	no definition for pain or acute pain	focal seizures, acute localized paroxysmal pain, identification for appropriate treatment.
Rivard P, 2001, USA	Orthopaedic Nursing	quality improvement	acute pain, children hospitalization, chronic disabilities	no definition for pain or acute pain	myths related to under treatment of pain, attitudes and knowledge affecting pain control practices, post-op management
Friedrichsdorf S., Remke S., Symalla B, Gibbon C., Chrastek J 2007, USA	International Journal of Palliative Nursing	opinion	acute pain, children, life-limiting condition, acute care environment	no definition for pain or acute pain	recurrent, chronic pain, palliative care, myths and misconceptions, acute pain service
Kennedy R, Luhmann J, Zempsky W, 2008, Canada	Pediatrics	opinion	acute pain, children, hospitalization, cancer	no definition for pain or acute pain	unmanaged needle insertion pain, memory, future impact, effects on child, family, care providers,
Mercadante, S., 2004, Italy	Pain Relief and Palliative Medicine	opinion	acute procedure - related pain, children		chronic disease related pain cancer, pain management factors related to inadequate treatment, myths related to children's pain

Table 2.4. Myths and Beliefs

Authors(s) and Year	Key Findings about Pain	Main Focus of Article
Breau L, Finley A, McGrath P, Camfield C, 2002	Lack of available and validated pain assessment tool, specific for children unable to give self report	Belief
Jacob E, Miaskowski C, Savedra M, Beyer J, Treadwell M, Styles L. , 2002	Failure on the part of the clinicians to perform ongoing pain assessments and evaluations on the effectiveness of the analgesic regimen. Inappropriate use of PCA devices Inappropriate titration of opioid analgesics	Belief, and Previous Findings
Meredith P, 1999	Increased hospitalizations resulting in less sensitivity to acute pain and a decrease in medical fears	Findings
Terstegen C, Koot H, deBoer J, Tibboel D, 2003	Communication difficulties on the part of the patient, increases the likelihood that pain will remain unrecognized and therefor untreated (inappropriate display of facial actions)	Belief, and Previous Findings
Charlesworth G, Soryal I, Smith S, Sisodiya S., 2008	None	
Rivard P, 2001	Children experience less pain than adults Persistent fears of cardio respiratory complications associated with pain relief medications Poor education of nurses in assessment or treatment measurements specific to childhood acute pain Pain management for children with chronic disabilities is different from pain in children with acute injury or illness, related to their increased need for multiple complex surgeries, spasticity or emotional anxiety	Myth and Belief

Table 2.4. Myths and Beliefs

Authors(s) and Year	Key Findings about Pain	Main Focus of Article
Friedrichsdorf S., Remke S., Symalla B, Gibbon C., Chrastek J 2007	Possibility of addiction with opioid use Possible respiratory depression or potential to hasten death with use of opioids	Myth
Kennedy R, Luhmann J, Zempsky W, 2008	Unmanaged pain can result in a variety of negative long-term consequences, altered development of pain sensation Newborn infants may actually experience pain more intensely than older children Memory of pain can increase subsequent reactions if poorly/inadequately managed (exaggerated memories, heightened stress) Impacts future procedures, through negative memories or increased need for analgesics Needle phobias, increased fear and anxiety Effects on parents or caregivers, specifically increased anxiety Effects on health care providers specifically the increased need for physical restraint and potential risk of injury, impact on moral, stress, as well as the increased time for the procedures themselves.	Belief, and Previous Findings
Mercadante, S., 2004	Inexperience and unfounded fears related to potential analgesics in both families and health care providers Poor understanding of basic pharmacokinetic principles Concerns of possible opioid addiction and respiratory depression	Belief, and Previous Findings

References

[1] Buscemi N, Vandermeer B, Curtis S. (2008) The Cochrane Library and Procedural Pain in Children: An Overview of Reviews. *Evidence-Based Child Health: A Cochrane Review Journal*, 3, 260-279.

[2] Davis MM, Brosco JP. (2007 Oct). Being Specific About Being Special: Defining Children’s Conditions and Special Health Care Needs. *Arch Pediatr Adolesc Med.* 161(10), 1003-1005.

[3] Stille CJ, Primack WA, Savageau JA. (2003 Dec). Generalist-subspecialist communication for children with chronic conditions: A regional physician survey. *Pediatrics*, 112(6), 1314-1320.

[4] Taylor EM, Boyer K, Campbell FA. (2008 Jan-Feb). Pain in hospitalized children: a prospective cross-sectional survey of pain prevalence, intensity, assessment and management in a Canadian pediatric teaching hospital. *Pain Res.Manag.*, 13(1), and 25-32.

[5] Van der Lee JH, Mokkink LB, Grootenhuis MA. (2007). Definitions and Measurement of Chronic Health Conditions in Childhood: A Systematic Review. *JAMA* 297(24), 2741-2751

[6] Ellis JA, O'Connor BV, Cappelli M, Goodman JT, Blouin R, Reid CW. (2002 Jul-Aug). Pain in hospitalized pediatric patients: how are we doing? *Clin.J.Pain*, 18(4), 262-269.

[7] Humphrey GB, Boon CM, van Linden van den Heuvell GF, van de Wiel HB. (1992 Jul). The occurrence of high levels of acute behavioral distress in children and adolescents undergoing routine venipunctures. *Pediatrics*, 90(1 Pt 1), 87-91.

[8] Cummings EA, Reid GJ, Finley GA, McGrath PJ, Ritchie JA. (1996 Nov). Prevalence and source of pain in pediatric inpatients. *Pain*, 68(1), 25-31.

[9] Kortesluoma RL, Nikkonen M. (2004 Sep). 'I had this horrible pain': the sources and causes of pain experiences in 4- to 11-year-old hospitalized children. *J.Child Health Care*, 8(3), 210-231.

[10] Johnston CC, Abbott FV, Gray-Donald K, Jeans ME. (1992 Jun). A survey of pain in hospitalized patients aged 4-14 years. *Clin.J.Pain*, 8(2), 154-163.

[11] Von Baeyer CL, Marche TA, Rocha EM, Salmon K. (2004 Jun). Children's memory for pain: overview and implications for practice. *J.Pain*, 5(5), 241-249.

[12] Stevens BJ, Abbott LK, Yamada J, Harrison D, Stinson J, Taddio A, Barwick M, Latimer M, Scott SD, Rashotte J, Campbell F, Finley GA. (2011). Epidemiology and management of painful procedures in children in Canadian hospitals. *CMAJ*, 187 (3), E403-E410.

[13] Stinson J, Yamada J, Dickson A, Lamba J, Stevens B. (2008 Jan-Feb). Review of systematic reviews on acute procedural pain in children in the hospital setting. *Pain Res.Manag*., 13(1), 51-57.

[14] Brennan-Hunter AL. (2001). Children's pain: A mandate for change. *Pain Research Management*, 6(1), 29.

[15] McGrath PJ, Walco GA., Turk DC, Dworkin RH, Brown MT, Davidson K, Eccleston C, Finley GA, Goldschneider K, Haverkos L, Hertz SH, Lungman G,

Palermo T, Rappaport BA, Rhodes T, Schechter N, Scott J, Sethna N, Svensson OK, Stinson J, von Baeyer C, Walker L, Weisman S, White RE, Zajicek A, Zeltzer L. (2008). Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. *Journal of Pain*, 9(9), 771-783.

[16] Breau LM, Finley GA, McGrath PJ, Camfield C. (2000). Validation of the Non-Communicating Children's Pain Checklist – Postoperative Version. *Anesth.*, 96, 528.

[17] International Association for the Study of Pain (IASP). SIG Position Statement. Available at: http://childpain.org/ Accessed 09/10/10

[18] American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health, Task Force on Pain in Infants, Children, and Adolescents. (2001 Sept). The assessment and management of acute pain in infants, children, and adolescents. *Pediatrics,* 108(3), 793-797.

[19] Anand KJ. International Evidence-Based Group for Neonatal Pain. (2001 Feb). Consensus statement for the prevention and management of pain in the newborn. *Arch.Pediatr.Adolesc.Med.*, 155(2), 173-180.

[20] International Association for the Study of Pain. IASP Pain Terminology. Available at: http://www.iasp-pain.org/AM/Template.cfm?Section=PainDefinitions. Accessed 07/15/10.

[21] Phillips DM. (2000). JCAHO pain management standards are unveiled. Joint Commission on Accreditation of Healthcare Organizations. *JAMA*, 284, 428-429.

[22] World Health Organization, International Association for the Study of Pain. (1998). Cancer pain relief and palliative care in children.

[23] Royal College of Nursing. Clinical Practice Guidelines: The recognition and assessment of acute pain in children, September 2009. Available at: http://www.rcn.org.uk/development/practice/pain/downloads. Accessed 07/21/10.

[24] Olmstead DL, Scott SD, Austin WJ. (2010). Unresolved pain in children: A relational ethics perspective. *Nursing Ethics*, 17(6), 695-704.

[25] Watt-Watson JH, Clark AJ, Finley A, Watson CP. (1999). Canadian Pain Society position statement on pain relief. *Pain Res Manage*, 4(2), 75-78.

[26] O'Halloran J, Miller GC, Britt H. (2004). Defining chronic conditions for primary care with ICPC-2. *Family Practice*, 21: 381-386.

[27] Anderson DM, Keith J, Novak PD, Elliot MA. Mosby's Medical, Nursing, & Allied Health Dictionary. 6th ed. (2002). Toronto, ON. Mosby.

[28] Jacob E, Miaskowski C, Savedra M, Beyer J, Treadwell M, Styles L. (2003). Changes in intensity, location and quality of vaso-occlusive pain in children with sickle cell disease. *Pain*, 102, 187-193.

[29] Meredith PS (1999). Response to acute pain among children with and without sickle cell disease. McGill University, 1-111.

[30] Terstegen C, Koot HM, deBoer JB, Tibboel D. (2003). Measuring pain in children with cognitive impairment: Pain response to surgical procedures. *Pain*, 103, 187-198.

[31] Charlesworth G, Soryal I, Smith S, Sisodiya S. (2009). Acute, localized paroxysmal pain as the initial manifestation of focal seizures: A case report and a brief review of the literature. *Pain*, 141, 300-305.

[32] Rivard P. (2001). Acute postoperative pain control for children with chronic disabilities. *Orthopaedic Nursing*, 20(1), 17-21.

[33] Friedrichsdorf SJ, Remke S, Symalla B, Gibbon C, Chrastek J. (2007). Developing a pain and palliative care programme at a US children's hospital. *International Journal of Palliative Nursing*, 13(11), 534-542.

[34] Kennedy RM, Lukmann J, Zempsky WT. (2008). Clinical implications of unmanaged needle insertion pain and distress in children. *Pediatrics*, 122, S130-S133.

[35] Mercandante S. (2004). Cancer pain management in children. *Palliative Medicine*, 18,654-662.

[36] Merskey H. (1979). Pain terms: A list with definitions and note on usage. *Pain*, 6,249-252.

[37] Barden J, Edwards JE, Mason L, McQuay HJ, Moore RA. (2004). Outcomes in acute pain trials: Systematic review of what was reported. *Pain*, 109, 351.

[38] Dosa NP, Boeing NM, Kanter RK. (2001). Excess Risk of Severe Acute Illness in Children with Chronic Health Conditions. *Pediatrics*, 107(3), 499.

[39] Hamilton JG. (1995 Aug). Needle phobia: a neglected diagnosis. *J.Fam.Pract.*, 41(2),169-175.

[40] Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. (1998). An Epidemiologic Profile of Children With Special Health Care Needs. *Pediatrics*, 102(1), 117-123.

[41] Uman LS, Chambers CT, McGrath PJ, Kisely S. (2008 Sep). A systematic review of randomized controlled trials examining psychological interventions for needle-related procedural pain and distress in children and adolescents: an abbreviated Cochrane review. *J.Pediatr.Psychol*., 33(8), 842-854.

Chapter 3: Acute Pain in Chronically Ill Hospitalized Canadian Children

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Acknowledgments: Ms Medynski is supported by the Canadian Institute of Health Research (CIHR) Team in Children's Pain – Master's Scholarship.

Dr. Scott is supported by a research personnel award from the Alberta Heritage Foundation for Medical Research, and a New Investigator award from the Canadian Institutes of Health Research.

1. Introduction

It has been previously identified that children in hospital undergo multiple painful procedures and receive less relief from their pain than they should [1,2], but little is understood why this is continually so despite a plethora of research and knowledge gain in the area. The development of numerous international pain guidelines and pain assessment tools, along with the identification and validation of safe pain management strategies has not resulted in significant improvement of the assessment and management of children’s acute pain [3-9]. Children with a chronic illness have been previously identified as a population at increased risk of receiving painful procedures while in hospital, but the majority of research involves very specific chronic diagnosis, which can be difficult to relate to the general chronically ill population that exists [10- 14]. This study seeks to identify children with a chronic illness in a generalized yet specific clearly defined nature to encourage the comparison with both previous and future research completed utilizing this population. In clearly defining a generalized and specifically identified chronically ill population we hope to gain insight into how these children differ from the acutely ill population of hospitalized Canadian children. This study seeks to gain knowledge of children’s acute pain experiences and assessments while in Canadian hospitals, to aid in the understanding of what the experience, management and assessment of acute pain in hospitalized children with a chronic illness is truly like.

2. Methods

2.1. Design

This study utilized an exploratory descriptive design to examine the frequency and nature of painful procedures and pain assessments in chronically ill children, while in hospital. This was accomplished through the use of secondary analysis of the CIHR Team in Children's Pain – Canadian Pediatric Pain Research (CPPR) Database.

2.2. Sample and Canadian Pediatric Pain Research Database

In the development of the Canadian Pediatric Pain Research (CPPR) database, medical charts of 3840 children were reviewed from 32 inpatient units within 8 Canadian pediatric hospitals. Data was recorded for the previous 24 hour period on the nature and frequency of painful procedures, assessment tools, and management interventions. This data collection occurred between October 2007 and April 2008. The CPPR dataset was the basis for my thesis work; it is the foundation of the CIHR Team in Children's Pain six year program of funded research. The CIHR Team in Children's Pain developed a data codebook and operational definitions, which were utilized and occasionally augmented during our secondary analysis of the data. By utilizing the CPPR database we explored the experience and assessment of pain experienced by children while in hospital, specifically with chronic illnesses. This was used to provide a snapshot of current practices related to pain in pediatric hospitals across Canada.

The World Health Organization (WHO) International Classification of Diseases (ICD) (http://apps.who.int/classifications/apps/icd/icd10online/), in combination with the Ontario Child Health Study (OCHS) classification of chronic illness in children, were utilized as the foundation for the Childhood Chronic Illness list (Appendix 1). These two categorical classification systems were combined and adjusted through the guided use of the definitions and criteria for chronic illness, specific to this thesis. Chronic illness was identified as an ‘illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. Chronic illness will certainly affect the person’s quality of life’ (www.chronicillness.org). The following criteria were required for the definition of chronic conditions. These conditions may have a duration that has lasted, or is expected to last at least 6 months, have a pattern of recurrence or deterioration, have a poor prognosis, produce consequences or sequelae that impact on the individual’s quality of life [15 – 21]. This type of categorical approach does have some limitations as not all of the disorders listed meet the diagnostic criteria or fit within the definition. The benefit of this approach is ultimately the generalizability as well as the overall specificity of a clearly defined list.

The sample of chronically ill children included in this study were obtained through examining and cleaning the primary and secondary diagnosis fields (fields 7and 8 of the CIHR Team in Children's Pain CPPR database), in order to isolate the children with a diagnosis present in the childhood chronic illness list. This list along with the definition and criteria specific to this thesis guided the combination of these two fields into one; specifying either an acute or chronic diagnosis for each child.

Ethics approval was received from the Human Ethics Research Board – Panel B, at the University of Alberta prior to data analysis. A Data Transfer Agreement was put in place by the Hospital for Sick Children (Toronto, ON) and the University of Alberta to transfer the anonymized data for secondary analysis. This data was stored and analyzed in the University of Alberta Faculty of Nursing Data Repository.

2.3. Data Analysis

Secondary analysis comes with advantages and disadvantages. A main advantage is that the data set is available therefore the data does not need to be collected. However this can also be a limitation as the data is received in an ‘as is’ state, thus no further information can be collected, or clarified [22].

There was little missing data in the CPPR. For the variables that we utilized, there were four instances of missing data for demographics, and 37 did not meet the inclusion criteria of age less than 18 years. We excluded these 41 cases, which resulted in a final sample of 3799 children.

Statistical analysis was performed using SPSS (version 19) initially for demographic characteristics, painful procedures and pain assessments obtained for completeness and consistency [23]. Extensive recontextualization and cleaning of the data into a more generalizable and usable theory was completed, so as to enable comparison with other literature to occur [24]. We calculated means, medians, and standard deviations (SD) for continuous data, and frequency counts and proportions for categorical data. We also used Chi square tests for categorical data, such as whether or not a particular type of assessment had been completed and if these variables were statistically different from each other to establish meaning. We specified a significance value of $p=0.05$ for all statistical tests.

2.4. Results

2.4.1.Participants

As previously noted the total sample of participants in this study was 3799; 53.1% were male in gender, and 46.9% were female. When looking specifically at the chronically ill population (N=1355), 52.5% were males and 47.5% were female. All participants were between the ages of 0 -18, with a noted predominance in children 4 years and younger (Total population – 51.8%, M= 6.43, SD= 6.081; Chronic illness population – 51.4%, M= 6.4, SD=6.011) (Table 3.1). This could be potentially in part due to the time of year in which data collection occurred, October to April. During this time evidence has shown infants and toddlers to be at elevated risk of hospitalization for influenza related complications regardless of prior health [25-27].

2.4.2. Chronic Diagnosis

When looking at the total population, 35.7% (1355) were found to have a diagnosis consistent with the general chronic illness list compiled for the purpose of this study. Over half of these 1355 children having a chronic diagnosis falling under the headings of 8- Diseases of the circulatory system (28.3%), 5- Diseases of the nervous system (18.0%), and 15- Congenital malformations, deformations and chromosomal abnormalities (11.1%) (Table 3.2). These three diagnostic categories accounted for more than half the chronically ill participants (57.4%). For example, congenital heart defects requiring repair, cardiomyopathy or heart transplant were included under diseases of the circulatory system. Epilepsy, severe cognitive delay, and hydrocephalus were a few of the most commonly listed diagnosis which fell under the heading of diseases of the nervous system. Trisomy 21, Crouzon’s and DiGeorge syndromes were a few of the diagnosis that fell under the heading of congenital malformations, deformations and chromosomal abnormalities.

The total population studied consisted of children from eight Canadian children's hospitals, specifically 32 units from which charts were extracted, of these 10 were critical care units, 14 were medical units and 8 were surgical units. The medical units alone accounted for the majority of the chronically ill population, 48.3 % (N=655) (Table 3.3).

2.4.3. Painful Procedures

When examining the data we concentrated on the experience of a painful procedure by hospitalized children with a chronic illness and examined whether the pain from these experiences was assessed, and if so by either a validated pain assessment tool or a non-validated pain assessment tool (i.e. RN narrative account). We found children admitted over a 24 hour period into a Canadian hospital received a minimum of one painful procedure 84.7% of the time (3217/3799). Of these children, those that fit into the chronic diagnosis category received a minimum of one painful procedure in 24 hours 86.2% of the time (1168/1355).

2.4.4. Pain Assessment Tools

We found that hospitalized Canadian children received assessment of their pain 68% of the time in a 24 hour period, regardless of diagnosis. The original data collection forms for the CIHR Team in Children's Pain consisted of 12 specific validated pain assessment tools, where as the CPPR database contained 24 validated pain assessment tools and 5 narrative non-validated pain assessment tools. The data showed 15 different validated pain tools were used to assess acute pain in our sample of chronically ill children, in comparison to the 18 different validated pain assessment tools used for acutely ill children in the 24 hours examined. When looking at the population of children with a chronic diagnosis the Numerical Rating Scale (0-10) was used most often (17.9%), FLACC was used 11.1% of the time and the checkbox was used 7.6% of the time. It was found that children with a diagnosis of chronic illness received a maximum of two validated pain assessment tools in the 24 hour period, with 87.9% only receiving one (Table 3.4).

The database consisted of numerous narrative or non-validated pain assessment tools were divided into groups depending on narrator. The narrators were stated to be an RN, MD, patient report, from the flow sheet or other nursing staff. These non-validated pain assessments consisted of the written description of the health care professionals account of the child's pain, sometimes a description of physical or behavioral actions or direct quotes from the patient of their pain experience. Due to time constrains and the difficulty condensing and analyzing this type of data we limited our analysis to the RN narrative assessments. The RN narrative assessments consisted of written documentation (nursing notes) such as "No complaints of pain; pt crying, irritable and difficult to console; pt appears comfortable". These accounted for the highest number of non-validated assessments in chronically diagnosed children, 17.1% (N=232). The remaining groups of non-validated narrative assessments accounted for less than 3.5 % of the total assessments completed in the preceding 24 hours (Table 3.5).

We used t-test to assess if children with a chronic diagnosis differed in their receipt of pain assessments, overall and either through validated or non-validated pain assessment tools. Upon running the analysis, we found there to be a statistical difference in the number of non-validated RN narrative pain assessment tools (nursing notes) used on chronically diagnosed children in comparison to children with an acute diagnosis (Chronic diagnosis N=1355, SD=1.225; Acute diagnosis N=2444, SD= 1.437; t=2.371, df=3797, Sig (2-tailed)= 0.018. These same groups were found not to differ significantly in their receipt of an overall pain assessment tool or their receipt of validated pain assessment tools.

3. Discussion

There has been limited research on acute pain experienced by children with chronic illness. Therefore, to facilitate valid comparisons across studies of the prevalence of acute pain in hospitalized children with chronic illnesses, international consensus about the conceptual definition of chronic health conditions in childhood [18-21] would be preferable. As a result of this lack of conceptual clarity, the findings emerging out of this study are potentially limited in terms of comparability to other research due to variation in the understanding of chronic illness definitions and criterion used [22, 29, 30]. For example the article by Bonnie Stevens and associates, which was recently published in the CMAJ and examined the same data set, stated a total of 29.8% of hospitalized Canadian children were found to have a chronic illness. These numbers were confirmed with the original dataset prior to cleaning. The difference in findings highlights the importance of clarity and cleaning when performing secondary analysis especially when multiple researchers are involved in the data collection process, regardless of training.

3.1. Study Implications

Current evidence on the incidence of chronic illness among children ranges from 5-31% depending on specificity of diagnostic inclusion/exclusion criteria of the population [18-21]. The findings from this study suggest that when utilizing a generalized yet clearly defined diagnostic criterion to examine chronic illness in children, approximately 35.7% of Canadian children hospitalized in a pediatric hospital will have a chronic illness. It is important to document how these criteria are established and utilized so that all research can be more easily compared on a variety of levels.

Through the statistical analysis of the largest Canadian hospitalized children's database known to date (CPPR), we found that children with a chronic diagnosis received a painful procedure 86.2% of the time, within a 24 hour period. These same children received an assessment of their pain 68% of the time in that same 24 hour period. When we looked at the overall number of pain assessment tools utilized in a 24 hour period there was a slight difference between the diagnosis groups. Chronically ill children received a maximum of two different validated pain assessments in a 24 hour period, were as acutely ill children received a maximum of three. We found a slight increase in the experience of a painful procedure for chronically ill children of 2.4% in contrast to acutely diagnosed children. Therefore one could suggest a slight decrease in assessment of chronically ill children's pain in Canada when compared to the acutely ill population in hospital.

When looking at the specific assessment tools used, they were not found to differ significantly between the groups (acute or chronic), as the top three validated assessment tools remained the same only shifting in the second and third choices, but still remaining consistent in accounting for 37% of the validated assessments (Total population – 36.9%; chronic diagnosis – 36.6%). For this study we found there to be a statistically significant difference in the number of RN narrative non-validated assessments performed on children with a chronic diagnosis in comparison to children with an acute diagnosis. When we processed this data through the use of cross tabs we found there to be a statistically significant difference between the use of validated pain assessment tools and the RN Narrative non-validated pain assessment tool (X2 = 394.606, df = 2, Sig = 0.000; Chronic diagnosis x2 = 131.463, df = 2, Sig = 0.000). Suggesting that there was a difference in the number of non-validated RN Narrative assessments completed for acute and chronically ill children. But when accounting for the other non-validated assessment tools utilized (MD, patient report, other nursing staff and flow sheet documentation), the differences were no longer statistically significant between these groups.

4. Limitations

This data is limited by the manner in which it was collected, specifically chart extraction. The main limitations with chart extraction being, that only the previous 24 hours of each chart was used, there was no direct discussion involved with the professionals documenting in the chart, and if documentation was absent or incomplete in the chart no other sources of documentation were accessed. Also this study was limited by the definitions specific to the CIHR Team in Children's Pain Project 1 Data Collection form, data codebook and operational definitions. As well as the definitions, and diagnostic criteria used to analyze the diagnosis.

5. Conclusions

When looking at Canadian pediatric hospitals, we found 35.7% of children admitted to have a chronic illness. Over half of these children were diagnosed with either a disease of the circulatory system, nervous system or congenital malformation, deformation and chromosomal abnormality (57.4% of all chronic illness diagnosis).

We found that hospitalized chronically ill Canadian children were likely to experience a painful procedure 85% of the time, yet only receive an assessment of their pain 68% of the time. Children with a chronic diagnosis received a painful procedure 2.4% over that of the acutely ill child, but no change in frequency or type of assessment was found.

It is important to note when talking of chronically ill children being at increased risk of pain we must keep in mind the data examined in this study looked at a 24 hour period of one hospitalization. Through research we know that chronically ill children are more likely to have increased length of stays while in hospital as well as frequent hospitalizations through out the course of their disease [10,14,19]. Therefore one might be inclined to conclude from this snap shot of data that Canadian children with a chronic diagnosis are at a significantly increased risk of experiencing pain that is likely to not be appropriately assessed.

The question that needs to be addressed next is if it is acceptable that Canadian hospitalized children predominantly receive one assessment of their pain 68% of the time, when 85% are likely to receive a painful procedure during the same 24 hour period.

Table 3.1 Descriptive Statistics of Sample

Descriptive	Total Population	Chronically ill Children
Age	N= 3799	N=1355
Minimum (in years)	0	0
Maximum (in years)	18	18
Mean	6.43	6.40
Standard Deviation	6.081	6.011
Gender		
Male	N=2018; 53.1 %	N=711; 52.5%
Female	N=1781; 46.9%	N=644; 47.5%

Table 3.2 Diagnostic Categories for Chronic Illnesses

Category	Frequency	Percent
1-Neoplasms	98	7.2
2- Diseases of the Blood and Blood forming organisms and certain disorders involving the immune mechanism	43	3.2
3-Endocrine, nutritional and metabolic diseases	62	4.6
4- Mental and behavioral diseases	31	2.3
5- Disease of the nervous system	244	18.0
6- Disease of the eye and adnexa	0	0
7- Diseases of the ear and mastoid process	0	0
8- Diseases of the circulatory system	383	28.3
9- Diseases of the respiratory system	115	8.5
10- Diseases of the digestive system	68	5.0
11- Diseases of the skin and subcutaneous tissue	0	0
12- Diseases of the musculoskeletal system and connective tissue	57	4.2
13- Diseases of the genitourinary system	53	3.9
14- Certain conditions originating in the perinatal period	12	0.9
15- Congenital malformations, deformations and chromosomal abnormalities	150	11.1
16- Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	39	2.9
Totals	**1355**	**100**

Table 3.3 Hospital Unit Breakdown

Hospital Unit Classification	Chronic Illness Diagnosis	Total Number (Percent)
Critical Care	467 (34.5%)	1181 (31.1%)
Medical	655 (48.3%)	1675 (44.1%)
Surgical	233 (17.2%)	943 (24.8)
Total	**1355**	**3799**

Table 3.4 Validated Pain Assessment Tools Used in a 24 Hour Period

Validated Pain Assessment Tool		First Assessment Tool Used*		Second Assessment Tool Used*	
#	Name	Frequency	%	Frequency	%
1	Numeric Rating Scale (0-10)	243	17.9		
2	Faces Pain Scale Revised (FPS-R)	3	0.2		
3	Visual Analogue Scale (VAS)	2	0.1		
4	4-Point Verbal Scale	4	0.3	3	0.2
5	Children's Hospital of Eastern Ontario Pain Scale	2	0.1		
6	Faces, Legs, Activity, Cry, Consolability (FLACC)	145	10.7	5	0.4
7	*AT Behavioral	23	1.7		
8	*AT Comfort Scale	8	0.6		
9	*AT Modified Comfort Scale	16	1.2		
10	*AT Glascow Coma Scale	2	0.1		
11	*AT Indicateurs Non Verbaux			1	0.1
12	*AT Neonatal Infant Pain Scale (NIPS)				
13	*AT Nurse's Pain Tool	31	2.3	22	1.6
14	*AT Oucher Scale				
15	*AT Poker Chip Tool				
16	*AT Scale for Use in Newborns (SUN)	12	0.9		
17	Tool NS	18	1.3		
18	Checkbox	56	4.1	47	3.5
18	Total Number of Pain assessments	565	41.7	78	5.8

*AT – Assessment Tool – not included in original data collection forms

*Validated Pain Assessment Tools Used for Children with a
Chronic Illness Diagnosis only

Table 3.5 Pain Assessment Tools

	Chronic Illness Population	
Experience of a Painful Procedure in the Previous 24 Hours	**Frequency**	**Percent**
Yes	1168	86.2
No	187	13.8
Assessment Tool Type	**Frequency**	**Percent**
Use of a Validated Assessment tool – Total in 24 hours	643	47.5
First Validated Pain Assessment Tool Used in 24 hours	565	41.7
Second Different Validated Pain Assessment Tool Used in 24 hours	78	5.8
Third Different Validated Pain Assessment Tool Used in 24 hours	0	0
Non Validated - Narrative RN Assessment Tool Used in 24 hours	232	17.1
*Total Assessments Analyzed in 24 hours	875	64.6
Non Validated Assessment Tool – Others not analyzed in 24 hours	47	3.5
**Total Overall Assessments Used in 24 hours	922	68

*Total Assessments Used in 24 hours – Validated plus RN Narrative Non Validated
** Total Overall Assessments Used including all non-validated tools not specifically examined in this article

References

[1] Walco GA, Cassidy RC, Schechter NL. Pain, hurt, and harm: The ethics of pain control in infants and children. The New England Journal of Medicine. 1994 August 25; 331:541-544.

[2] Stevens BJ, Abbott LK, Yamada J, Harrison D, et al. Epidemiology and management of painful procedures in children in Canadian hospitals. CMAJ. 2011, DOI:10.1503/cmaj.101341.

[3] Stinson J, Yamada J, Dickson A, Lamba J, Stevens B. Review of systematic reviews on acute procedural pain in children in the hospital setting. Pain Res.Manag. 2008 Jan-Feb; 13(1): 51-57.

[4] Yamada J, Stinson J, Lamba J, et al. A review of systematic reviews on pain interventions in hospitalized infants. Pain Res. Manag. 2008; 13: 413-420.

[5] Batton DG, Barrington KJ, Wallman C. Prevention and management of pain in the neonate: an update. Pediatrics 2006; 118: 2231-2241.

[6] Berry PH, Dahl JL. Making pain assessment and management a healthcare system priority through the new JCAHO pain standards. Journal of Pharma. Care Pain Symptom Control 2000; 8:5-20.

[7] Taylor EM, Boyer K, Campbell FA. Pain in hospitalized children: a prospective cross-sectional survey of pain prevalence, intensity, assessment and management in a Canadian pediatric teaching hospital. Pain Res.Manag. 2008 Jan-Feb; 13(1): 25-32.

[8] Johnston CC, Barrington KJ, Taddio A, et al. Comfort measures for pain in Canadian NICU’s: Have we improved in the past decade? [Abstract]. In: Proceedings of the 19th annual meeting of the Pediatric Academic Society; 2008 May 3-8: Honolulu

(HI). E-PAS2008:634454.13. Available: www.abstract2view.com/pasall/(accessed 2011 Oct).

[9] American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health, Task Force on Pain in Infants, Children, and Adolescents. The assessment and management of acute pain in infants, children, and adolescents. Pediatrics 2001 Sep; 108(3): 793-797.

[10] Dosa NP, Boeing NM, Kanter RK. Excess Risk of Severe Acute Illness in Children with Chronic Health Conditions. Pediatrics 2001; 107(3): 499.

[11] Mercadante S. Cancer pain management in children. Palliative Medicine 2004; 18(7): 654-662.

[12] Barden J, Edwards JE, Mason L, McQuay HJ, Moore RA. Outcomes in acute pain trials: Systematic review of what was reported. Pain 2004; 109: 351.

[13] Von Baeyer CL, Marche TA, Rocha EM, Salmon K. Children's memory for pain: overview and implications for practice. J.Pain 2004 Jun; 5(5): 241-249.

[14] Buscemi N, Vandermeer B, Curtis S. The Cochrane Library and Procedural Pain in Children: An Overview of Reviews. Evidence-Based Child Health: A Cochrane Review Journal 2008; 3:260-279.

[15] O'Halloran J, Miller GC, Britt H. Defining Chronic Conditions for Primary Care with ICPC – 2. Family Practice 2004; 21:381-386.

[16] International Association for the Study of Pain. IASP Pain Terminology. Available at: http://www.iasp-pain.org/AM/Template.cfm?Section=Pain_Definitions. Accessed 09/15/2008.

[17] World Health Organization, International Association for the Study of Pain. Cancer pain relief and palliative care in children. 1998.

[18] Van der Lee JH, Mokkink LB, Grootenhuis MA. Definitions and Measurement of Chronic Health Conditions in Childhood: A Systematic Review. JAMA 2007; 297(24): 2741-2751.

[19] Perrin JM, Bloom SR, Gortmaker SL. The Increase of Childhood Chronic Conditions in the United States. JAMA 2007: 297(24): 2755-2759.

[20] Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. An Epidemiologic Profile of Children With Special Health Care Needs. Pediatrics 1998; 102(1): 117-123.

[21] Davis MM, Brosco JP. Being Specific About Being Special: Defining Children's Conditions and Special Health Care Needs. Arch Pediatr. Adolesc. Med. 2007 Oct; 161(10): 1003-1005.

[22] Doolan DM, Froelicher ES. Using an Existing Data Set to Answer New Research Questions: A Methodological Review. Research & Theory for Nursing Practice 2009; 23(3): 203-215.

[23] Howitt D, Cramer D. Introduction to SPSS statistics in psychology: For version 19 and earlier. 5th revised edition, March 2011. Pearson Custom Publishing.

[24] Morse JM, Field PA. Qualitative Research Methods for Health Professionals, 2nd ed. 1995. SAGE Publications: Thousand Oaks, CA.

[25] Center for Disease Control and Prevention (CDC). Seasonal influenza – associated hospitalizations in the United States. 2011. Available at: http://www.cdc.gov/flu/about/qa/hospital.htm. Accessed 10/20/2011.

[26] Hoen AG, Buckeridge DL, Charland KML, et al. Effect of expanded US recommendations fro seasonal influenza vaccination: comparison of two pediatric emergency departments in the United States and Canada. CMAJ. 2011 Sept 20; 183(13)E1025-36.

[27] MacDonald N, Onyett H, Bortolussi R, Canadian Paediatric Society, Infectious Diseases and Immunizations Committee. Managing seasonal and pandemic influenza in infants, children and youth. Available at: http://www.cps.ca/english/publications/SeasonalPandemicFlu.pdf. Accessed 10/20/2011.

[28] Hazard Munro B. Statistical methods for health care research, 5th ed. 2005. Lippincott Williams & Wilkins: New York, NY.

[29] Brennan-Hunter AL. Children's pain: A mandate for change. Pain Research Management 2001: 6(1): 29.

[30] Ellis JA, O'Connor BV, Cappelli M, Goodman JT, Blouin R, Reid CW. Pain in hospitalized pediatric patients: how are we doing? Clin.J.Pain 2002 Jul-Aug; 18(4): 262-269.

Chapter 4: Summary of Results, Contributions, Implications and Limitations

1. Summary

In the previous chapters, I presented two papers that comprise the substantive position of my paper-based thesis. The aim of the thesis was to first summarize the literature regarding acute pain in hospitalized chronically ill children. Then summarize and explore the current practices in relation to acute pain in hospitalized chronically ill children across eight children's hospitals in Canada, through the analysis of data from the CIHR Team in Children's Pain using the Canadian Pediatric Pain Research (CPPR) network database. In addition to summarizing the findings further discussing the research practice implications, as well as the limitations of the combined studies.

1.1. Paper 1: *Acute Pain in Hospitalized Chronically Ill Children: A Critical Review*

This paper reported the findings of an integrative review of the literature pertaining to acute pain in chronically ill children, while in hospital. The initial search obtained 525 studies. The searches were further narrowed using limiting terms, than the abstracts of the remaining articles were evaluated for relevance to the present study using pre-determined inclusion criteria. Of these, 9 articles fit my criteria. The final 9 articles included in the review were sorted into three categories, experimental (n=4), quality improvement (n=2) and opinion (n=3).

1.2. Paper 1: Contribution

This is the first literature review that I am aware of that explores specifically acute pain in hospitalized chronically ill children, in as broad a sense of the definitions as possible. It explores the author's use or lack of use of definitions for pain and acute pain.

Only one article (Meredith) clearly defines both of these key terms. These articles all included hospitalized chronically ill children but differed greatly in their narrowed populations of study. Two of the experimental articles (Breau, and Terstegen) looked at children with profound cognitive impairment and their experiences of acute post-operative pain. Were as the articles by Meredith and Jacobs in this category, looked at children with sickle cell disease, but differed drastically in their examination of the acute pain experience. The opinion articles by Kennedy and Mercadante explored children with cancer's response to acute procedural pain. The article by Freidrichsdorf was the broadest in its population of children with life limiting conditions, specifying a distinct four-group classification system for ease of comparison and understanding (Table 2.3).

The articles were compared regarding their discussions of pain myths, beliefs and findings. Specifically the differences between chronically ill and acutely ill children in relation to: 1) acute pain; 2) their increased needs and risks; 3) their response to subsequent pain and fears; 4) risks and beliefs regarding opioid use; and 5) the generalized consensus that health care professionals lacked overall education and understanding of acute pain and chronically ill children (Table 2.4).

1.3. Paper 2: *Canadian Hospitalized Children's Experience of Acute Pain*

This study provided a snapshot of current health care practices involving acute pain in chronically ill children in Canadian children's hospitals. Through the use of a broad yet clearly defined definition of chronic illness in children this study seeks to encourage comparisons with past and future research. This study adds to the knowledge and understanding of children's acute pain experiences and assessments while in

Canadian hospitals, specifically identifying how this experience may differ between acute and chronically ill populations.

1.4. Paper 2: Contribution

Through secondary analysis of the CIHR Team in Children's Pain – Canadian Pediatric Pain Research (CPPR) database along with an exploratory descriptive design we examined the frequency and nature of painful procedures and pain assessments in hospitalized Canadian children.

A sample of 3799 children from 32 inpatient units within 8 Canadian pediatric hospitals were examined using SPSS (version 19). There was found to be a noted predominance of children ages 0 – 4 years, potentially related to the time of year in which the data was collected (October – April). We found children with a chronic illness to account for 35.7% of the study population. These children received a minimum of one painful procedure 86.2% of the time in a 24 hour period. We found that Canadian children were likely to receive an assessment of their pain 68% of the time regardless of their diagnosis. With 87.9% of these children only receiving a minimum of one assessment in the preceding 24 hour period and a maximum of two.

When we looked at the use of validated versus non-validated pain assessment tools the RN Narrative assessment was the only one to statistically differ from the rest. This assessment tool was used approximately 1/5th of the time (17.1% for children with a chronic illness).

2. **Summary of Contributions**

The contributions that this thesis makes to research literature are as follows:

1. First literature review to look broadly at acute pain in the hospitalized chronically ill child.
2. A snapshot of current practices and experiences in relation to acute pain in hospitalized chronically ill children across Canada. Key findings included:
    a. 35.7% of Canadian children in Pediatric hospitals were found to have a diagnosis consistent with the general chronic illness list compiled for the purpose of this study.
    b. Chronically ill children receive painful procedures 84.7% of the time in a 24 hour hospitalized period, yet they only received an assessment of this pain 68% of the time.
    c. Children with a chronic illness were found to receive a painful procedure 2.4% over that of acutely ill children with no change in frequency of type of assessments performed.
    d. Hospitalized chronically ill children were found to receive a maximum of two different validated pain assessments in a 24 hour period.
    e. Non-Validated pain assessment tools specifically RN narrative assessments account for a significant portion of pain assessments children received while in hospital (17.1%).

3. Implications

3.1. Research Implications

My findings bring to light that current pediatric pain research is primarily disease specific, often with extensively limited study inclusion criteria, and lacking in key term definitions to allow for clear understanding and comparison. Many researchers comment on the key to improved practice beginning with improved assessment, which would likely impact and lead to better management due to the increased recognition and acknowledgement of the presence of pain. As a result there is a plethora of research on creating and validating numerous population specific pain assessment tools. The result is that there is little change in the current practices of pain assessment. More has to be done to find out why this research on new and population specific resources are not being used effectively to diminish the effects of acute pain on hospitalized children.

3.2. Practice Implications

3.2.1. Chapter 2

The literature review helps to identify current international beliefs and practices related to the identification, assessment and management of hospitalized chronically ill children’s experience of acute pain. It helps to increase awareness that hospitalized children are often inadequately treated for pain and understanding of how children with a chronic illness may be at greater risk to experience pain while in hospital. This knowledge may be what is necessary for health care professionals to recognize the importance and need for initial and ongoing pain assessment and timely prevention and treatment regimens. This knowledge should contribute to greater understanding, there by decreasing the current mismanagement of acute pain by highlighting key areas were change and/or research are needed. The main goal is to increase the ability to create new or improved methods of practice to decrease the detrimental effects of acute pain on children with a chronic illness, while in hospital.

4. Limitations

4.1. Paper 1

The findings of our review suggested that much of the current research on pain in chronic illness is disease specific, or extensively limited in study inclusion criteria, as seen within the articles discussed. This limits the generalizability of the findings, isolating the research and diminishing the idea of 'chronic illness' in children is as an all-encompassing term. This specificity and changing criteria helps to explain why there is such a large discrepancy in the overall estimates of chronic illness in children (5-31%) [1,2].

In the literature review we explored a variety of concerns and barriers in using or creating standardized pain measurement tools within pediatrics. A few of the barriers which confound the use of these pain measurement tools were differing patient ages, developmental levels, and linguistic abilities used to describe children's perceptions of acute or chronic pain. These barriers result in confusion not only for researchers but clinicians as well, leaving many to question the true prevalence of acute pain and the effectiveness of current treatment options and practices. Majority of available literature does not clearly state why certain pain assessment tools were used for their specific populations, or discuss how the pain tools used may be applicable or compare to other tools used for differing populations. Despite these difficulties, many international associations believe that the drive to create appropriate standardized pain measurement tools is the best way to attempt to clarify current practices in a clear and concise manner, and to allow for further comparison between studies.

The findings from this literature review identify current international clinical practices and thoughts related to the identification and assessment of hospitalized chronically ill children experiencing acute pain. This contributes to the overall knowledge and understanding of acute pain in chronically ill children, with the potential of decreasing the overall mismanagement of pain in children, by identifying necessary next-steps for further studies.

4.2 Paper 2

This study was a secondary analysis. The data is limited by the manner in which it was originally collected, specifically chart extraction. The main limitations with chart extraction were, 1) only the previous 24 hours of each chart was used, 2) there was no direct discussion involved with the professionals documenting in the chart, 3) if documentation was absent or incomplete in the chart no other sources of documentation were accessed and 4) there were multiple data extractions by a number of different collectors.

There has been limited research on acute pain experienced by children with chronic illness. Therefore, to facilitate valid comparisons across studies of the prevalence of acute pain in hospitalized children with chronic illnesses, consensus of the conceptual definition of chronic health conditions in childhood would be preferable if not necessary in some considerations [3-6]. As a result of this lack of conceptual clarity, the findings emerging out of this thesis are potentially limited in terms of comparability to other research due to variation in the understanding of chronic illness definitions used.

5. Knowledge Translation

All products generated through this thesis will be disseminated at the completion of the entire thesis in accordance with the CIHR Team in Children's Pain guidelines and approval processes. The research analysis will be disseminated through end of grant knowledge translation activities. This study produced two manuscripts that will be submitted for publication in peer-reviewed journals. The content will be customized to target child health service professionals and researchers, primarily in fields related to chronic illness and pain. Traditional mechanisms for disseminating the results from both papers will be utilized, in areas such as publications in peer reviewed, executive summary fact sheets disseminated at local venues and to key stakeholders, presentation of study findings at a local conference. This will allow for discussion and the potential to build upon the research findings in future projects. It also allows for opportunity for the researcher to be challenged on the results and to defend the quality of the research completed.

6. Conclusions

The research completed and literature written on pediatric acute pain has aided in dispelling some of the myths related to pain in children, and identified areas for further research and investigation, but this has not been translated into significant practice changes, as seen by the analysis on chronically ill Canadian children. This includes the formulation and testing of assessment measures specific to the diverse characteristics of this pediatric population, specific enough for a variety of age and developmental levels, but general enough to be used for differing pain categories (acute vs. chronic). Many researchers believe the key to encouraging better management is better assessment. This premise then facilitates improved detection and monitoring of pain, and decreases the chance that pain will be discounted or minimized in the clinical environment. As shown in this study acute pain assessment occurs around 68% of the time, improving or creating additional assessment tools may not be the only answer to the problem. By reviewing current literature on acute pain in hospitalized chronically ill children, researchers and clinicians are encouraged to examine further possible better ways of identifying, assessing and managing pediatric pain. The ultimate goal being to create new or improved methods of decreasing the short and long term detrimental effects of acute pain on an ever-growing population, of chronically ill children. Assessing how these assessment tools are utilized in the practice areas may be helpful in exploring the use or effectiveness of pain assessment care guidelines, as well as the knowledge and understanding of health care providers, children and their families of the different pain assessment tools available.

By acknowledging that children with a chronic illness have an elevated risk for poor recognition and undermanaged pain, health care professionals are increasing their potential to act and improve in the overall detection and management of this pain.

References

[1] Barden J, Edwards JE, Mason L, McQuay HJ, Moore RA. Outcomes in acute pain trials: Systematic review of what was reported. Pain 2004; 109: 351.

[2] Dosa NP, Boeing NM, Kanter RK. Excess Risk of Severe Acute Illness in Children with Chronic Health Conditions. Pediatrics 2001; 107(3): 499.

[3] Van der Lee JH, Mokkink LB, Grootenhuis MA. Definitions and Measurement of Chronic Health Conditions in Childhood: A Systematic Review. JAMA 2007; 297(24): 2741-2751.

[4] Perrin JM, Bloom SR, Gortmaker SL. The Increase of Childhood Chronic Conditions in the United States. JAMA 2007: 297(24): 2755-2759.

[5] Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. An Epidemiologic Profile of Children With Special Health Care Needs. Pediatrics 1998; 102(1): 117-123.

[6] Davis MM, Brosco JP. Being Specific About Being Special: Defining Children’s Conditions and Special Health Care Needs. Arch Pediatr. Adolesc. Med. 2007 Oct; 161(10): 1003-1005.

Appendices

Appendix A: Childhood Chronic Illness List

Appendix B: CIHR Team in Children's Pain: Canadian Pediatric Pain Research Database: Data Collection Forms

Appendix A

Childhood Chronic Illness List

This list was created through the combination of the previously identified definitions of chronic illness specified within this study, the WHO International Statistical Classification of Diseases and Related Health Problems (10th Revision) and the Ontario Child Health Study (OCHS) classification of chronic illness in children.

I. Neoplasms
  - Malignant neoplasms
  - Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissue
  - Lip, oral cavity and pharynx
  - Digestive Organs
  - Respiratory and intrathoracic organs
  - Bone and articular cartilage
  - Skin
  - Mesothelial and soft tissue
  - Breast
  - Female genital organs
  - Male genital organs
  - Urinary tract
  - Eye, Brain and other parts of the central nervous system
  - Thyroid and other endocrine glands
  - Malignant neoplasms of ill-defined, secondary and unspecified sites
  - Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue
  - Malignant neoplasms of independent (primary) multiple sites
  - In situ neoplasms
  - Benign neoplasms
  - Neoplasms of uncertain or unknown behavior

II. Diseases of the blood and blood forming organs and certain disorders involving the immune system
  - Haemolytic anaemias
  - Aplastic and other anaemias
  - Coagulation defects, purpura and other haemorrhagic conditions
  - Other diseases of the blood and blood forming organs
  - Certain disorders involving the immune mechanism

III. Endocrine, nutritional and metabolic disorders
  - Disorders of the thyroid gland
  - Diabetes mellitus
  - Other disorders of glucose regulation and pancreatic internal secretion
  - Disorders of other endocrine glands
  - Metabolic disorders
  - Other nutritional deficiencies
  - Obesity and other hyperalimentation

IV. Mental and behavioral disorders
  - Organic, including symptomatic, mental disorders
  - Mental and behavioral disorders due to psychoactive substance use
  - Schizophrenia, schizotypal and delusional disorders
  - Mood (affective) disorders
  - Neurotic, stress-related and somatoform disorders
  - Behavioral syndromes associated with physiological disturbances and physical factors
  - Mental retardation
  - Disorders of psychological development
  - Behavioral and emotional disorders with onset usually occurring in childhood and adolescence
  - Unspecified mental disorder

V. Diseases of the nervous system
  - Inflammatory diseases of the central nervous system
  - Systemic atrophies primarily affecting the central nervous system
  - Extrapyramidal and movement disorders
  - Other degenerative diseases of the nervous system
  - Demyelinating diseases of the central nervous system
  - Episodic and paroxysmal disorders
  - Nerve, nerve root and plexus disorders
  - Polyneuropathies and other disorders of the peripheral nervous system
  - Diseases of myoneural junction and muscle
  - Cerebral palsy and other paralytic syndromes
  - Other disorders of the nervous system

VI. Diseases of the eye and adnexa

VII. Diseases of the ear and mastoid process

VIII. Diseases of the circulatory system
  - Chronic rheumatic heart disease
  - Hypertensive diseases
  - Ischaemic heart diseases
  - Pulmonary heart disease and diseases of pulmonary circulation
  - Other forms of heart disease
  - Cerebrovascular diseases
  - Diseases of arteries, arterioles and capillaries
  - Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified
  - Other and unspecified disorders of the circulatory system

IX. Diseases of the respiratory system
  - Diseases of the upper respiratory tract
  - Chronic lower respiratory diseases
  - Lung diseases due to external agents
  - Other respiratory diseases principally affecting the interstitium
  - Suppurative and necrotic conditions of lower respiratory tract
  - Other disease pleura
  - Other diseases of the respiratory system

X. Diseases of the digestive system
  - Diseases of oral cavity, salivary glands and jaw
  - Diseases of the oesophagus, stomach and duodenum
  - Noninfective enteritis and colitis
  - Other diseases of the intestines
  - Diseases of the peritoneum
  - Diseases of the live
  - Disorders of gallbladder, biliary tract and pancreas
  - Other diseases of the digestive system

XI. Diseases of the skin and subcutaneous tissue
  - Bullous disorders
  - Papulosquamous disorders
  - Radiation-related disorders of the skin and subcutaneous tissue
  - Disorders of skin appendages

XII. Diseases of the musculoskeletal system and connective tissue
  - Inflammatory polyarthropathies
  - Arthrosis
  - Other joint disorders
  - Sympathetic connective tissue disorders
  - Deforming dorsopathies
  - Spomdylopathies
  - Disorders of synovium and tendon
  - Disorders of bone density and structure
  - Chondropathies
  - Other disorders of the musculoskeletal system and connective tissue

XIII. Diseases of the genitourinary system
  - Glomerular diseases
  - Renal tubulo-intestinal diseases
  - Renal failure
  - Urolithiasis
  - Other disorders of kidney and ureter
  - Other diseases of urinary system
  - Diseases of male genital organs
  - Inflammatory and non-inflammatory disorders of female pelvic organs and genital tract
  - Other disorders of the genitourinary tract

XIV. Certain conditions originating in the perinatal period
  - Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery
  - Disorders related to length of gestation and fetal growth
  - Birth trauma
  - Respiratory and cardiovascular disorders specific to the perinatal period
  - Haemorrhagic and haematological disorders of fetus and newborn

- Transitory endocrine and metabolic disorders specific to fetus and newborn?
- Digestive system disorders of fetus and newborn
- Conditions involving the integument and temperature regulation of fetus and newborn
- Other disorders originating in the perinatal period

XV. Congenital malformations, deformations and chromosomal abnormalities
  - Congenital malformations of the nervous system
  - Congenital malformations of the eye, ear, face and neck
  - Congenital malformations of the cardiovascular system
  - Congenital malformations of the respiratory system
  - Cleft lip and cleft palate
  - Other congenital malformations of the digestive system
  - Congenital malformations of the genital organs
  - Congenital malformations of the urinary system
  - Congenital malformations and deformations of the musculoskeletal system
  - Other congenital malformations
  - Chromosomal abnormalities not elsewhere classified

XVI. Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified

XVII. External causes of morbidity and mortality

Appendix B

CIHR Team in Children's Pain: Canadian Pediatric Pain Research Database: Data Collection Forms

CIHR Team in Children's Pain:
Canadian Pediatric Pain Research Database

Child Socio-Demographic Data Collection Form

1. Date patient chart recruited	(YYYY-MM-DD)	
2. Time patient chart recruited	(HHMM 24 –hr clock)	
3. Birth date	(YYYY-MM-DD) (indicate the year + month + which half of the month the child was born: 01 or 16)	
4. Gender	☐ Male	☐ Female
5. Weight of patient	(kg)	
6. Date of admission to unit (most recent unit)	(YYYY-MM-DD)	
7. Primary diagnosis	☐ Acute	☐ Chronic
8. Secondary diagnosis	☐ Acute	☐ Chronic

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

UNIT PROFILE FORM

Hospital , Unit

The information you provide should be reflective of the past full month: e.g. September 15 - October 15 (2007-09-15 to 2007-10-15).

1. Define the 1-month reporting period: (YYYY-MM-DD) to (YYYY-MM-DD)

For the one-month period from _____________ to ________on the ________ unit:

2. What was the average number of occupied beds on this unit?

3. What was the average length of patient stay (in days) in the past month?

4. What was the total number of patient days in the past month?

5. What was the age range of children on the unit? (If age was < 2 years, indicate age in months)

Youngest months ☐/ yrs ☐ to oldest months ☐/ yrs ☐

6. How many children of each age were admitted?

0-12 mos 13-23 mos 2-4 yrs 5-8 yrs 9-12 yrs > 12 yrs

7. Describe the (dedicated) staff on your unit.
In the Number column, report the total number of staff, by role, in each category (full-time, part-time, etc).
In the FTE column, add up the full-time equivalent rates of each of the staff members, by role, in each category for the total FTE.
Example: if you have 5 Full-Time Registered Nurses on your unit, 4 of which are 1.0 FTE and one is 0.8 FTE, you would enter 5 in the "Number" column and 4.8 in the "FTE" column.

Position	**Applicable to this unit?**		**Full-time Staff**		**Part-time Staff**		**Casual Staff**		**Vacant Positions**	
	Yes	**No**	**Number**	**FTE**	**Number**	**FTE**	**Number**	**FTE**	**Number**	**FTE**
Registered Nurses	☐	☐								
Licensed Practical Nurses	☐	☐								
Managers/Supervisors	☐	☐								
Charge Nurse/Clinical Support Nurse	☐	☐								
Educators	☐	☐								
CNS/NP	☐	☐								
Pharmacists	☐	☐								
Respiratory Therapists	☐	☐								
Rehabilitation Therapists	☐	☐								
Child Life Workers	☐	☐								
Social Workers	☐	☐								
Dieticians	☐	☐								
Others (Please specify)	☐	☐								
Others (Please specify)	☐	☐								
Others (Please specify)	☐	☐								

8. Is this a University/College/Diploma-affiliated teaching unit? Yes ☐ No ☐

Enter a value for the number of trainees in every position on the unit.

Position	Yes	No	Number of Trainees
Medical fellows	☐	☐	
Medical residents	☐	☐	
Medical students	☐	☐	
Nursing students	☐	☐	
LPN students	☐	☐	
Respiratory therapy students	☐	☐	
Paramedic students	☐	☐	
Other (please specify)	☐	☐	
Other (please specify)	☐	☐	
Other (please specify)	☐	☐	
Other (please specify)	☐	☐	
Other (please specify)	☐	☐	

9. Did your unit have access to an Acute Pain Service/ Pain Management Team? Yes ☐ No ☐

Did your unit consult with the Acute Pain Service/Pain Management Team? Yes ☐ No ☐

On average how many times per week would you consult with the Acute Pain Service/Pain Management Team? Times/week

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

CHILD PAINFUL PROCEDURE DATA COLLECTION FORM

Were the following painful procedures used within the past 24 hours?
(Indicate yes or no, the number of times used and whether an intervention was used for all procedures).

1	Were any painful procedures performed over the past 24 hours?	☐ Yes	☐ No

		Painful procedure used?			Intervention used with this procedure?				
2	Capillary sampling	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
3	IV insert + blood sampling	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
4	Venepuncture/phlebotomy	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
5	Injections: subcutaneous (SC)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
6	Injections: intramuscular (IM)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
7	Injections: intradermal (ID)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
8	Injections: joint	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
9	Peripheral intravenous attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

10	Peripheral intravenous removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
11	Peripheral arterial line attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
12	Peripheral arterial line removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
13	Long line attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
14	Long line removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
15	Central venous line attempt or insertion - in OR	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
16	Central venous line attempt or insertion – not in OR	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
17	Central venous line removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
18	Accessing Port-a-cath	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
19	Chest tube attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
20	Chest tube in situ	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
21	Chest tube removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

22	Nasogastric (NG) tube attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
23	Nasogastric (NG) tube in situ	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
24	Nasogastric (NG) tube removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
25	Orogastric (OG) tube attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
26	Orogastric (OG) tube in situ	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
27	Orogastric (OG) tube removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
28	Nasojejunal (NJ) tube attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
29	Nasojejunal (NJ) tube in situ	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
30	Nasojejunal (NJ) tube removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
31	Endotracheal tube (ETT) attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
32	Endotracheal tube (ETT) in situ	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
33	Endotracheal tube (ETT) removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

34	Nasopharyngeal (NP) tube attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
35	Nasopharyngeal (NP) tube in situ	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
36	Nasopharyngeal (NP) tube removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
37	Umbilical line attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
38	Umbilical line removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
39	Urinary catheter attempt or insertion/supra pubic aspiration	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
40	Urinary catheter removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
41	Tenckhoff catheter attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
42	Tenckhoff catheter removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
43	Hemodialysis catheter attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
44	Hemodialysis catheter removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
45	Peritoneal dialysis	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

46	Lumbar puncture or attempt		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
47	ECMO cannulation		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
48	ECMO decannulation		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
49	Surgery	☐general	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
50		☐cardiovascular	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
51		☐neurosurgery	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
52		☐orthopaedic	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
53		☐urology	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
54		☐ears/nose/throat (ENT)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
55		☐ophthalmology	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
56		☐plastics	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
57		☐dental	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

58		☐haematology/ oncology	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
59		☐gastrointestinal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
60		☐image guided therapy (IGT)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
61		☐gynaecology	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
62		☐respirology	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
63	Tape removal from skin		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
64	Suture removal		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
65	Staple removal		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
66	Pin removal		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
67	Adjustment/cleaning of pins: external fixators		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
68	Adjustment/cleaning of pins: halo traction		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
69	Dressing change/removal		☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

70	Scrapings/swabs: allergy scrapes	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
71	Scrapings/swabs: nasopharyngeal swabs	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
72	Scrapings/swabs: culture/specimen	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
73	Biopsy: skin	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
74	Biopsy: muscle	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
75	Scopes: colonoscopies	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
76	Scopes: endoscopies	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
77	Suctioning: oral or nasal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
78	Suctioning: endotracheal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
79	Wound irrigation	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
80	Wound debridement/burn care	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
81	Mobilization	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

82	Traction with weights	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
83	Casting	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
84	Retinopathy of prematurity (ROP) eye exam	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
85	Transesophageal echo (TEE)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
86	Tracheotomy care	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
87	Pericardial drain attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
88	Pericardial drain removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
89	External ventricular drain attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
90	External ventricular drain removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
91	Jackson-Pratt drain attempt or insertion	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
92	Jackson-Pratt drain removal	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
93	MRI under GA	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

94	CT under GA	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
95	Cleaning/care of excoriated skin	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
96	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
97	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
98	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
99	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
100	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
101	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
102	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
103	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych
104	Other (please specify)	☐ Yes	☐ No	Times	☐ Yes	☐ No	☐ Pharm	☐ Physical	☐ Psych

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

CHILD PAIN ASSESSMENT PROFILE

Were the following pain assessment tools used within the past 24 hours?
(If yes, please indicate the number of times this pain assessment tool was used over the past 24 hour period).

Yes	No		
☐	☐	1. Were any pain assessment tools used over the past 24 hours?	

Yes	No		Scores
☐	☐	2. Premature Infant Pain Profile (PIPP)	
☐	☐	3. Douleur Aigue du Nouveau-ne (DAN)	
☐	☐	4. Numeric Rating Scale (0-10)	
☐	☐	5. Faces Pain Scale Revised (FPS-R)	
☐	☐	6. Visual Analogue Scale (VAS)	
☐	☐	7. 4-Point Verbal Scale	
☐	☐	8. Non-Communicating Children's Pain Checklist (NCCPC-R)	

☐	☐	9. Non-Communicating Children's Pain Checklist (Post-op Version) (NCCPC-PV)	
☐	☐	10. Neonatal Pain, Agitation, and Sedation Scale (N-PASS)	
☐	☐	11. Children's Hospital Eastern Ontario Pain Scale (CHEOPS)	
☐	☐	12. Face, Legs, Activity, Cry, Consolability (FLACC) Scale	
☐	☐	13. Other pain scales used (please specify)	
☐	☐	14. Other pain scales used (please specify)	
☐	☐	15. Other pain scales used (please specify)	
☐	☐	16. Other pain scales used (please specify)	
☐	☐	17. Other pain scales used (please specify)	
☐	☐	18. Other pain scales used (please specify)	
☐	☐	19. Other pain scales used (please specify)	
☐	☐	20. Other pain scales used (please specify)	

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

CHILD PHARMACOLOGICAL INTERVENTIONS PROFILE

Record each medication this patient received in the past 24 hours with the respective dosing information.
If the same medication was given at different doses, enter the information for each dose separately.

		Yes	No
1	Were any medications given to this patient over the past 24 hours?	☐	☐

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
2	☐	☐	Non-opioids	Acetaminophen PO							
				Acetaminophen PR							
3	☐	☐	NSAIDs	Diclofenac PO							
				Diclofenac PR							
				Ibuprofen PO							
				Indomethacin PO							
				Ketolorac IV							
				Ketolorac IM							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Naproxen PO							
				Naproxen PR							
4	☐	☐	Sucrose	Sucrose PO					Solution %		
5	☐	☐	Opioids	Codeine IV Bolus Infusion							
				Codeine PO							
				Codeine SC							
				Codeine + Acetaminophen IV Bolus							
				Codeine + Acetaminophen PO							
				Fentanyl Dermal							
				Fentanyl Epidural							
				Fentanyl IV Bolus							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Fentanyl IV Bolus Infusion							
				Fentanyl IV Infusion							
				Hydromorphone Epidural							
				Hydromorphone IV Bolus							
				Hydromorphone IV Bolus Infusion							
				Hydromorphone IV Infusion							
				Hydromorphone PO							
				Hydromorphone PR							
				Hydromorphone: Long-Acting IV Bolus Infusion							
				Hydromorphone: Long-Acting PO							
				Meperidine IM							

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Meperidine IV							
				Meperidine IV Bolus Infusion							
				Meperidine PO							
				Methadone IV Bolus Infusion							
				Methadone PO							
				Morphine Epidural							
				Morphine IV Bolus							
				Morphine IV Bolus Infusion							
				Morphine IV Infusion							
				Morphine PO							
				Morphine PR							

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Morphine SC							
				Morphine: Long-Acting IV Bolus Infusion							
				Morphine: Long-Acting PO							
				Oxycodone IV Bolus Infusion							
				Oxycodone PO							
				Oxycodone: Long-Acting IV Bolus Infusion							
				Oxycodone: Long-Acting PO							
				Percocet IV Bolus Infusion							
				Percocet PO							
				Tramacet IV Bolus Infusion							
				Tramacet PO							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Tramadol IV Bolus Infusion							
				Tramadol PO							
6	☐	☐	Adjuvants	Clonidine Dermal							
				Clonidine PO							
				Ketamine Epidural							
				Ketamine IV Bolus							
				Ketamine IV Infusion							
				Ketamine PO							
7	☐	☐	Anticonvulsants	Carbamazepine PO							
				Clonazepam PO							
				Gabapentin PO							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Lamotrigine PO							
				Phenobarbitol IV							
				Phenobarbitol PO							
				Pregabalin PO							
				Topiramate PO							
				Valproic acid PO							
				Vigabatrin PO							
8	☐	☐	Antidepressants	Amitryptyline PO							
				Duloxetine PO							
				Nortriptyline PO							
				Venlafaxine PO							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
9	☐	☐	Benzodiazepines	Diazepam IV Infusion							
				Diazepam PO							
				Lorazepam IV Bolus							
				Lorazepam IV Infusion							
				Lorazepam PO							
				Midazolam IV Bolus							
				Midazolam IV Infusion							
				Midazolam PO							
10	☐	☐	Sedatives for Procedures	Chloral Hydrate PO							
				Chloral Hydrate PR							
				Pentobarbital IV							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Pentobarbital PO							
11	☐	☐	General Anaesthetics	General Anesthesia							
12	☐	☐	Local Anaesthetics	Bupivacaine Epidural							
				Bupivacaine SC							
				Lidocaine SC							
				Ropivacaine Epidural							
				Ropivacaine SC							
				Tetracaine Epidural							
				Tetracaine SC							
13	☐	☐	Topical Anaesthetics	Amethocaine Dermal							
				Lidocaine-Prilocaine Dermal							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Liposomal Lidocaine 4% Cream Dermal							
14	☐	☐	Anticholinergics	Belladonna and Opium PR							
				Buscopan/Hyoscine N-Butylbromide IV							
				Buscopan/Hyoscine N-Butylbromide PO							
15	☐	☐	Antiemetics	Dexamethasone IV							
				Dexamethasone PO							
				Dimenhydrinate IV							
				Dimenhydrinate PO							
				Metoclopramide IV							
				Metoclopramide PO							
				Nabilone IV							

	Yes	No			Route	Drug Amount	Unit	Total Doses Received	Solution Amount (mL)	Infusion Rate (mL/hr)	Infusion Duration (hh:mm)
				Nabilone PO							
				Ondansetron IV							
				Ondansetron PO							
16	☐	☐	Other								
17	☐	☐	Other								
18	☐	☐	Other								
19	☐	☐	Other								
20	☐	☐	Other								
21	☐	☐	Other								
22	☐	☐	Other								

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

CHILD PHYSICAL INTERVENTIONS PROFILE

Were any physical interventions performed over the past 24 hours?
(If yes, please indicate the number of times this physical intervention was used over the past 24 hour period).

		Yes	No	
1	Were any physical interventions performed over the past 24 hours?	☐	☐	

		Yes	No	Times
2	Breastfeeding	☐	☐	
3	Breathing Exercises	☐	☐	
4	Comforting/Reassurance	☐	☐	
5	Comfort Positioning/ Bundling/ Containing /Swaddling/ (Infants)	☐	☐	
6	Distraction for Infants	☐	☐	
7	Facilitated Tucking	☐	☐	
8	Healing Touch/Therapeutic Touch	☐	☐	

9	Heat/Cold Therapy	☐	☐	
10	Massage/Tactile Stimulation	☐	☐	
11	Medical Staff Coaching	☐	☐	
12	Non-Nutritive Sucking (e.g. Pacifiers)	☐	☐	
13	Skin-to-Skin Contact (Kangaroo Care)	☐	☐	
14	Spot Pressure/Counter-Irritation	☐	☐	
15	Vestibular and Kinesthetic Stimulation	☐	☐	
16	Transcutaenous Electrical Nerve Stimulation (TENS)	☐	☐	
17	Other (please specify)	☐	☐	
18	Other (please specify)	☐	☐	
19	Other (please specify)	☐	☐	
20	Other (please specify)	☐	☐	

CIHR TEAM IN CHILDREN'S PAIN:
CANADIAN PEDIATRIC PAIN RESEARCH DATABASE

CHILD PSYCHOLOGICAL INTERVENTIONS PROFILE

Were any psychological interventions performed over the past 24 hours?
(If yes, please indicate the number of times this psychological intervention was used over the past 24 hour period).

		Yes	No	
1	Were any psychological interventions performed over the past 24 hours?	☐	☐	

		Yes	No	Times
2	Art Therapy	☐	☐	
3	Behavioural/External Distraction	☐	☐	
4	Cognitive (Mental) Distraction	☐	☐	
5	Coping Self-Statements	☐	☐	
6	Desensitization	☐	☐	
7	Hypnosis	☐	☐	
8	Imagery	☐	☐	

9	Medical Play	☐	☐	
10	Memory Change	☐	☐	
11	Modeling	☐	☐	
12	Music Therapy, Auditory Stimulation	☐	☐	
13	Parent Coaching	☐	☐	
14	Parent Training	☐	☐	
15	Positive Reinforcement	☐	☐	
16	Progressive Muscle Relaxation (PMR) Training	☐	☐	
17	Preparation/Education/Information	☐	☐	
18	Rehearsal	☐	☐	
19	Relaxation Training	☐	☐	
20	Suggestion	☐	☐	

21	Thought-stopping	☐	☐	
22	Virtual Reality	☐	☐	
23	Other (please specify)	☐	☐	
24	Other (please specify)	☐	☐	
25	Other (please specify)	☐	☐	
26	Other (please specify)	☐	☐	
27	Other (please specify)	☐	☐	
28	Other (please specify)	☐	☐	
29	Other (please specify)	☐	☐	
30	Other (please specify)	☐	☐	
31	Other (please specify)	☐	☐	
32	Other (please specify)	☐	☐	