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Pain assessment and management in paediatric oncology: a cross-sectional audit

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TITLE PAGE

Title

Pain assessment and management in paediatric oncology: a cross-sectional audit

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ABSTRACT

Aims and Objectives: To describe the pain assessment and management practices documented by health professionals within a tertiary Children's Cancer Centre and to evaluate how these practices compare with international recommendations.

Background: Children with cancer are vulnerable to pain due to the intensity of antineoplastic therapy. Therefore, it is imperative to ensure that current pain management practices provided to paediatric oncology in-patients is of a high quality.

Design: A single site cross-sectional audit.

Methods: A 24-hour period of documented pain-related care in randomly selected in-patients of an Australian tertiary level Children's Cancer Centre were examined. The current pain management practices were audited over a two-month period resulting in 258 episodes of pain related care being reviewed.

Results: Pain related to medical treatment for cancer was common ($n=146/258$, 57%) and persistent. The presence of pain was not consistently recorded by health professionals ($n=75/146$, 51%). Pain was mild ($n=26/75$, 35%) and opioids were the mainstay of pain

management interventions (n=63/112, 56%). Adjuvants were an important component of pain management (n=47/112, 42%) and nonpharmacological methods of managing pain were under-represented in this audit (n=38/146, 26%). According to the Pain Management Index, pain was appropriately managed for the majority of children (n=65/76, 87%).

Conclusion: Pain management practices did not fully reflect the recommendations of contemporary pediatric pain management. Due to limitations in the documentation of childrens pain it was difficult to determine the effectiveness of pain management interventions.

Relevance to clinical practice:

This study highlights the ongoing problem of pain for children receiving antineoplastic therapy. It is recommended that health professionals routinely screen for the presence of pain during hospitalisation and assess the efficacy of pain-related care.

Key words:

Children; Cancer; Pain; Pain assessment; Pain management; Quality of care

SUMMARY BOX

What does this paper contribute to the wider global clinical community?

1. Pain related to medical treatment for children with cancer was complex with pain persistent and reliant on the use of opioid therapy.
2. There is evidence that health professionals are more likely to provide pain management interventions when pain intensity scores have been documented.
3. The quality of pain management was hindered by the limited options for pharmacological interventions due to the toxic effects of antineoplastic therapy. It is recommended that nurses provide a multimodal approach to relieving pain by encouraging the use of non-pharmacological pain management interventions.

INTRODUCTION

Intense and prolonged treatment protocols for paediatric oncological diseases have resulted in cure rates of over 80% for children living in developed nations (Altekruse et al. 2010). A significant outcome of these treatments however, is pain (Kestler & LoBiondo-Wood 2012). Pain in children receiving antineoplastic therapy is common, persistent and experienced at high levels of intensity (Van Cleve et al. 2012). All children experience pain at some point during their cancer diagnosis or antineoplastic treatment and the presence of pain is often underestimated, undertreated and associated with significant fear and distress (Twycross et al. 2015, Wolfe et al. 2015).

BACKGROUND

Due to the success of antineoplastic therapy in curing children with cancer, it is unlikely that the intensity of this treatment will diminish and consequently, pain will continue to dominate as a symptom of paediatric cancer treatment (Williams et al. 2012). Targeted strategies need to be directed towards relieving pain for children with cancer as inadequately-managed pain has major consequences for the child, their family and health professionals involved in their care (Lu et al. 2011, McCarthy et al. 2013). Guidelines have been developed in paediatric oncology to facilitate adequate pain assessment and management (World Health Organization 1998, 2012). However, the literature continues to reveal a high symptom burden from pain for children receiving antineoplastic therapy (Kestler & LoBiondo-Wood 2012, Miller et al. 2011, Wolfe et al. 2015).

When addressing the problem of pain for children with cancer, most studies have focused on determining the prevalence and severity of pain in paediatric oncology. (Ellis et al. 2003, Finley et al. 2008, Forgeron et al. 2006). Importantly, these prior studies have highlighted that inequities exist in the pain-related care provided to children with cancer yet very few studies have considered the effectiveness of analgesic therapy for children hospitalised for antineoplastic therapy (Oakes et al. 2011, Zernikow et al. 2008, Zernikow et al. 2006). As paediatric oncology patients are usually unwell due to the toxic impact of antineoplastic therapy, they are highly reliant on health professionals to identify that they have pain and act accordingly on it (Craig 2009, Schiavenato & Craig 2010). Therefore, children with cancer are vulnerable to the impact of pain and it is imperative to review the current pain management practices provided to paediatric oncology in-patients to ensure that the delivery of pain-related care is standardised across patients and consistently of a high quality.

The aims of this study were to audit the documented pain management practices relating to the assessment and management of pain in children hospitalised in a tertiary level Children's Cancer Centre and to evaluate how these practices compared with international recommendations for high quality paediatric and cancer pain management (Gordon et al. 2005, World Health Organization 1998).

METHODS

Study design and setting

A single site, cross-sectional audit was conducted of in-patient medical records at the Children's Cancer Centre (CCC), at The Royal Children's Hospital (RCH), Melbourne, Australia. The CCC is located within a tertiary level paediatric hospital and consists of an 18-bed ward dedicated for general oncology care and an 8-bed Haematopoietic Stem Cell Transplantation (HSCT) unit. The CCC had specialist resources available for the treatment of pain. A procedural pain service with the aim to minimise pain and distress associated with children's cancer treatment was delivered by specialist allied health clinicians (child life/occupational therapists). A children's pain management service was also available to the CCC for advice on the management of complex pain-related care. At the time of data collection, a clinical practice guideline outlining the institutional expectations for pain assessment did not exist at the RCH. However, on the clinical observation chart there were 3 main pain assessment tools recommended for use: (1) The Face, Legs, Activity, Cry and Consolability (FLACC) scale, (2) The Wong Baker Faces Pain Scale (WBFPS) and (3) The Visual Analogue Scale (VAS).

Sample

The sample included paediatric patients who were: (1) aged 0-18 years if age, (2) current in-patient on the CCC oncology ward or HSCT unit and (3) had duration of stay of at least 24 hours. Patients were excluded if any part of the minimal 24-hour admission period occurred in a ward outside of the CCC.

Measures

Based upon guidelines of the World Health Organization (WHO) (World Health Organization 1998) and the American Pain Society (Gordon et al. 2005), a quality scorecard was designed as an audit tool for data collection (Donnelly et al. 2010). The Quality Score Card was piloted for clarity and ease of use by the first author (KP) and minor modifications made before starting the study.

Information collected with the Quality Score Card reflected seven domains of pain-related care documented by health professionals: (1) patient demographics, (2) pain assessment, (3) pain management, (4) pain documentation, (5) monitoring of processes and outcomes of pain management, (6) interdisciplinary pain care and (7) efficacy of pain management practices (Gordon et al. 2005) (Table 1). The efficacy of pain-related practices was investigated with the Pain Management Index (PMI). The PMI compares the most potent analgesics administered with the level of pain intensity to determine adequacy of pain management.

To calculate the PMI the Quality Score Card was reviewed to determine the strongest analgesic administered and the highest level of pain intensity during the EPOC. A score for the strongest analgesic administered was calculated according to the WHO analgesic ladder: 0 (no analgesia), 1 (non-opioid analgesia), 2 (weak opioid) and 3 (strong opioid). Next, a pain score was calculated from the highest level of pain intensity documented during the EPOC: 0 (no pain), 1 (mild), 2 (moderate) and 3 (severe). The PMI was then calculated by subtracting pain scores from analgesia scores. The PMI ranges from -3 (patient with severe pain receiving no analgesia) to +3 (patient receiving strong opioids and reporting no pain). Negative scores are generally indicative of under-treatment of pain, whilst a zero indicates appropriate treatment of pain. Positive scores ≥ 1 are not necessarily indicative of the over-treatment of pain as the use of strong opioids could contribute to low pain scores (Cleeland et al. 1997, Cleeland et al. 1994, Larue et al. 1995, Strohbuecker et al. 2005, Taylor et al. 2008).

Procedures

Ethics approval was gained from The Royal Children's Hospital Human Research Ethics Committee (HREC # 31064 A). Considering the low risk nature of this audit of in-patient

charts, consent from participants was not required. Using the quality scorecard, the documented pain management practices of health professionals were examined in the CCC. Specifically, a 24-hour period of pain-related care for eligible patients was audited. The 24-hour review period was designated an episode of care (EPOC) and commenced at 0800 hours on the previous day and concluded at 0800 hours on the day that the audit was conducted. This period for the EPOC is supported in the literature as a sufficient period of time to achieve a comprehensive picture of pain management practices (Taylor et al. 2008).

Eligible patients were randomly selected for auditing of their in-patient chart to avoid selection bias and to ensure that a representative sample of participants was obtained. An eligible patient list was generated at 0800 hours on the day of the audit and Microsoft Excel (2010) used to generate a random list of “A”s and “B”s. Any eligible patient matched with an “A” was assigned to in-patient chart auditing with the Quality Score Card by the first author (KP). Evidence that pain was present during an EPOC was defined by the documentation of one or more of the following criteria: (1) documentation of a pain intensity score in the nursing observation chart, (2) narratives documented by health professionals about the patient’s pain and (3) documentation of analgesics being administered (Taylor et al. 2008).

To provide a snapshot of the typical pain-related care provided by health professionals, each day of the week was consecutively audited (Saturday – Friday). This process was repeated 4 times over a two-month period to increase the likelihood that the documented practices of pain-related care were representative of the CCC. This process resulted in 28 days of pain-related care being reviewed between October 13th and December 14th, 2012. Due to the complexity of care in the CCC, and the potential for long admission periods, eligible patients could be audited at more than one time point.

Statistical analysis

Study data were entered into the REDCap (Research Electronic Data Capture) database (Harris et al. 2009) then exported into Minitab 16 Statistical Software (2010) for statistical analysis (Arend 2010) by the first author (KP). Statistical analysis was undertaken at two levels. Firstly, data obtained from the patient medical record audit tool was analysed using descriptive statistics at the level of the 258 EPOCS. Frequencies, ranges, means and standard deviations (SD) were calculated. For distributions that did not adhere to the normal curve,

medians and interquartile ranges were computed. Secondly, to examine differences between categorical variables, chi-square analyses were performed at the level of the 73 individual participants.

RESULTS

During the audit period, 259 EPOCs from 74 paediatric oncology in-patients were randomly selected to be audited. One patient was excluded due to admission to the Intensive Care Unit for a proportion of the EPOC. The final analysis included 258 EPOCs in 73 paediatric oncology in-patients, representing 47% of eligible in-patient charts. The flow chart of the data collection processes is outlined in Figure 1.

Demographics

Demographic data related to the 258 EPOCs are presented in Table 2. Of the 258 EPOCs, the sample included mainly male patients (59%) and the median age of participants was 4 (IQR 2,9) years. Most participants were diagnosed with blood cancers (49%); there was an under-representation of children with brain tumors, probably because these children are cared for at the time of surgery on a neurosurgical ward. The EPOCS also captured data for children with a non-malignant condition receiving HSCT therapy (n=37, 15%) and were included in the final sample as their care involved antineoplastic treatment. The median length of stay at the time of audit was 10 days (IQR 4,35) and admission was mostly for medical therapy associated with antineoplastic treatment (77%). The final sample for the 258 EPOCs included data related to 73 paediatric oncology in-patients. Children were audited an average of 3 times (range 1-14) during their in-patient stay.

Pain assessment

Pain was evident in 146 (57%) of the EPOCs (n=258) reviewed for pain-related care and documented. The cause of pain was documented in 34% (n=49) of EPOCs, with mucositis being the most common cause of pain (n=25, 51%). The location of pain was documented in 82 (56%) of EPOCs (n=146), with an average of 1.3 locations of pain identified. The most frequently documented locations of pain were consistent with mucositis and included the

perianal (n=23, 21%), mouth (n=20, 19%), abdomen (n=18, 17%) and throat (n=17, 16%) regions.

In the 146 situations where there was evidence of pain (n=146), 51% (75/146) of EPOCs had a pain intensity documented in the patients' observation chart. When a pain intensity was documented (n=75), the median number of pain assessments documented across the 24-hour-period was 1 (IQR 1,3) (Table 3). The type of pain assessment tool used to assess pain was documented in 1 (1/146, 0.7%) EPOC and was a Faces Pain Scale. No EPOCs recognised the functional outcomes of pain with a documentation of pain intensity on rest and movement.

Health professionals documented pain intensity scores on an 11-point scale (0=no pain, 1-3=mild pain, 4-6=moderate pain, 7-10=severe pain) (Macintyre et al. 2010). Of those EPOCs where pain intensity was documented (n=75), pain was mostly mild (median 1, IQR 1,3) (Table 4). A chi-square test of independence was performed to examine the relation between maximal pain intensity (none, mild, moderate/severe) and length of stay (0-30, 31-250 days). The relationship between pain intensity and length of stay was significant, χ^2 (2, n=55)=6.808, p=0.03 with mild pain more likely to persist beyond ≥ 31 days of hospitalisation.

Pain management

Analgesics were administered for 77% (122/146) of EPOCs with evidence of pain despite the majority of EPOCs having a valid analgesic prescription (129/146, 88%) available. A total of 238 analgesics were administered to children with a mean of 2.1 (SD 1.6, range 1-7) different analgesic medications per EPOC (n=112) with pain. Of the analgesics administered, 48% (114/238) were prescribed as pre re nata (prn) and 42% (100/238) as scheduled analgesics. When analgesia was prescribed as scheduled, 99% of the prescribed analgesics were administered as opposed to 74% of the analgesics prescribed as whenever needed. A further 8% (n=20) of analgesics were prescribed as a once-only administration and 2% (n=4) as nurse-initiated analgesia. No analgesics were delivered via the intramuscular route. A chi-square test of independence was performed to examine the relationship between the number of pain assessments (0, 1-3, 4-14) per EPOC and analgesia administered (yes, no). The relationship between these variables was significant, χ^2 (2, n=55)=10.739, p=0.005 with children more likely to receive analgesia if a pain assessment was documented.

Of the 112 (77%) EPOCs where analgesics were administered, children were most frequently managed on Step 3 of the WHO analgesic ladder with strong opioids (n=61, 55%), followed by Step 1 with simple analgesics (n=49, 44%) and Step 2 with weak opioids (n=2, 1%). Paracetamol was the only simple analgesic prescribed and weak opioids prescribed included tramadol and codeine. Strong opioids prescribed included morphine, hydromorphone, fentanyl, oxycodone and endone. The use of adjuvant medication was documented in 47 (42%) of the 112 EPOCs where analgesia was administered. Adjuvants prescribed for enhancement of analgesia included gabapentin, ketamine, clonidine, hyoscine butylbromide, diazepam and amitriptyline. Where analgesia was administered (n=112), half of the children received unimodal analgesic therapy (n=57, 51%). Figure 2 provides further information regarding the single or combined drug therapies administered for the 112 EPOCs where analgesia was administered.

Of the EPOCs where there was evidence of pain, 26% (38/146) of episodes documented 44 non-pharmacological pain management interventions. The documented interventions for the non-pharmacological management of pain are presented in Table 4. Where a non-pharmacological intervention was documented (n=38), 34% (n=13) of the EPOCs did not concurrently receive a pharmacological pain management intervention. A chi-square test of independence was performed to examine the relation between the documentation of a non-pharmacological intervention (yes, no) and age (0-2, 3-7, 8-18) in years. The relationship between these variables was significant, $\chi^2 (2, N=55) = 9.432, p=0.009$ with children < 8 years of age more likely to have a non-pharmacological intervention documented.

Pain documentation

When there was evidence of pain, information about pain was documented for 87% (127/146) of the EPOCs. Documentation was mostly undertaken by nurses (n=145, 70%), followed by medical officers (n=49, 22%) and allied health team members (n=16, 8%). In total, 319 characteristics about the sensory (n=207, 65%), treatment-related (n=85, 27%) and the behavioural (n=27, 8%) factors related to pain were documented. Table 5 provides a summary of the different ways that health care providers documented pain.

Interdisciplinary and collaborative pain care

The involvement of a specialist pain management service was documented in 9% (13/146) of EPOCs where pain was evident. The majority of consultations for pain with the specialist service were for the management of pain associated with Hematopoietic Stem Cell Transplantation (12/146, 92%). Pain management plans were documented by health professionals in 22% (32/146) of EPOCs where pain was evident. The haematology and oncology clinical database was reviewed to determine if the procedural pain service had documented an individualised plan specific for the management of procedural pain. A procedural pain plan was documented in 7% (10/146) of EPOCs.

Monitoring of processes and outcomes of pain management

Documentation of monitoring for adverse events was minimal and a documented adverse event rarely occurred. These adverse events included 2 episodes of sedation and 1 episode of morphine withdrawal. A medical review due to pain was documented in 7% (10/146) of the EPOCs. Sedation scores were documented for 39% (44/122) of EPOCs where analgesics were administered and aperients were concurrently administered for 31% (19/61) of the EPOCs where opioids were provided.

Efficacy of pain management practices

To assess the adequacy of pain management treatment, the Pain Management Index (PMI) was calculated for the EPOCs (n=76) where a pain intensity was documented either in the patients observation chart (n=75) or in their medical record (n=1). A PMI of zero was calculated for a 17% (n= 13/76) and a PMI greater than zero calculated for 68% (n=52) of EPOCs (n=75), suggesting that with a median pain intensity of 0 (IQR 0,3) on an 11-point scale, the majority of EPOCs (n= 64, 84%) had appropriate management according to the intensity of pain. Although a $PMI \geq 1$ could be interpreted as over-treatment of pain, Taylor et al. (2008) recommend that this may be a result of low pain intensity scores because pain is being controlled with strong opioids. Fifteen percent of EPOCs (n=11) had a PMI less than zero indicating that pain was under-treated. Specifically, no analgesia was administered during the EPOCs with a PMI less than zero (11/76) despite a mean maximum pain intensity

of 3.1 (SD 1.6, range 1-5), indicating mild to moderate pain. The distribution of the PMI is summarised in Table 6.

DISCUSSION

This study provides a detailed snapshot of pain-related care within an Australian tertiary paediatric oncology setting. The results confirm that pain related to medical treatment for cancer was common and persistent. The finding that 57% of EPOCs had evidence of pain is consistent with previous studies (Forgeron et al. 2006, Ljungman et al. 1996, Treadwell et al. 2002, Zernikow et al. 2006), however, the prevalence of pain in this sample is likely to be under-reported as most children were pre-verbal (≤ 3 years). Pre-verbal children are limited in their capacity to self-report pain and are therefore reliant on caregivers to estimate pain intensity based on their ability to express pain through their behaviour (van Dijk & Tibboel 2012, World Health Organization 2012).

In contrast to similar studies of pain in hospitalised children published within the last 5 years (Birnie et al. 2014, Groenewald et al. 2012, Harrison et al. 2014, Kozłowski et al. 2014, Shrestha-Ranjit & Manias 2010, Twycross & Collis 2013), this study's results suggest that children have had their pain managed appropriately due to the minimal levels of moderate to severe pain documented. However, children were provided with limited opportunities for their pain to be made highly visible as only half (51%) of EPOCs had pain documentation, demonstrating a median of 1 pain assessment per 24-hour period. Such documented pain practices might relate to an absence of guidelines for the frequency of pain assessment in medical settings at this institution. Nonetheless, the frequency of documented assessments in this study is less than expected considering the majority of this cohort with pain received opioid therapy (55%).

Documented pain management practices were largely aligned with international recommendations for paediatric pain and oncology pain management (Gordon et al. 2005, World Health Organization 1998). Whilst opioids were the mainstay of pharmacological management, our results demonstrate that a multimodal approach to analgesic prescription was evident, with intermittent analgesia also provided when required. The WHO's (World Health Organization 2012) updated guideline, released in late 2012, now supports a two-step analgesic ladder with weak opioids for the treatment of moderate pain no longer

recommended (World Health Organization 2012). Our study shows clinical practice matching the WHO's guideline (World Health Organization 2012) with the minimal use of weak opioids administered at the historical step 2 of the analgesic ladder (World Health Organization 2012).

There were documented pain management practices that occurred outside the recommendations of the WHO (World Health Organization 1998, 2012) and the American Pain Society (Gordon et al. 2005). A multimodal approach to pain management that combines both opioid and non-opioid agents alongside adjuvant therapy in an attempt to improve analgesia is recommended (Gordon et al. 2005, World Health Organization 1998, 2012), yet was not always evident in this study. Although multimodal analgesia was prescribed, half (51%) of the EPOCs where analgesia was provided were unimodal. Although the singular administration of non-opioids (30%) may be appropriate for the management of mild pain, 21% of the EPOCs involved the singular administration of an opioid or adjuvant. Where opioids were administered singularly, narratives in the medical history indicated that analgesic options were considered limited due to concerns with antineoplastic therapy induced organ dysfunction. The administration of opioids can be complex, and at times risky, for children with medical illnesses (World Health Organization 2012). However, there was limited involvement of a dedicated children's pain service (9%) in managing pain with opioids and adjuvant medications. Results indicate that there was also minimal communication of children's pain amongst health professionals through the documentation of pain management plans in the medical records (22%). Additionally, it is proposed that procedural pain, which is more episodic and has different pain management strategies, has not been captured in the documentation of health professionals.

Non-pharmacological pain management strategies were also under-represented in this study with just 26% of the EPOCs with evidence of pain recording a non-pharmacological intervention. It is possible that the documentation of non-pharmacological interventions may be under-estimated (Harrison et al. 2014, Zhu et al. 2012). There is also a concern that non-pharmacological interventions may have been a substitute for adequate analgesic treatment. When a non-pharmacological intervention was documented, 34% did not concurrently receive a pharmacological intervention. Another concern is related to the under-utilisation of sucrose as only 3 administrations were documented despite 10% of the cohort being ≤ 1 year of age. The finding regarding sucrose for infants is consistent with those of a previous

observational study of procedural pain management at this institution's Day Oncology unit (McCarthy et al. 2013).

The PMI indicates that appropriate analgesia was provided for most children (86%), with minimum adverse outcomes (2%) documented. However, whether the PMI truly reflects effective pain management practices is questionable due to limitations in the documentation of pain. The PMI could only be calculated for 52% of EPOCs with pain where both a pain intensity and analgesic administration were documented. The mild pain documented could be the result of the ability to pre-emptively manage pain in children with cancer due to the predictable time course of painful complications associated with antineoplastic therapy (Zernikow et al., 2006). Furthermore, the administration of strong opioids in the setting of low pain intensity scores could be a reflection of the limited choices for analgesia to treat mild to moderate pain in the paediatric oncology setting. Alternatively, the low pain intensity scores documented could also be a reflection of incongruities in the pain assessment practices of health professionals. It is postulated that pain was documented when it was mild due to gaps in the understanding of validated paediatric pain assessment tools and the reliance on proxy methods of pain assessment by health professionals.

The most common method that health professionals use for measuring pain in children is a self-report of pain intensity with the Numerical Rating Scale (NRS)(Stinson et al. 2006, Tomlinson et al. 2010). The NRS is only recommended for use with children ≥ 8 years of age as children need to have developed the ability to express their pain quantitatively to reliably use this tool(Stinson et al. 2006). However, only 30% (n=44) of the EPOCs with pain involved children within this age range. The majority of EPOCs with pain involved children aged < 4 years (46%, n=69), who are considered too young to understand pain assessment scales (McGrath et al. 2008, von Baeyer & Spagrud 2007). Thus, observation of pain-related behaviour should have been the principal method of assessing pain intensity. Yet, observation of pain-related behaviours are open to misinterpretation and proxy measures of pain assessment may underestimate the severity of pain (Byrne et al. 2001, Mattsson et al. 2011, Shum et al. 2012, Twycross 2007). Nonetheless, as the type of assessment tool used to obtain a pain intensity score was not documented for 99% of EPOCs with pain, it is unclear how pain was actually assessed for this cohort of children.

LIMITATIONS

There are limitations of this study that require consideration. As this study was based on an audit of documented pain practices it is possible that the pain related care provided by health care providers in real time has not been fully captured. Additionally, the prevalence pain may also be under-reported, however, the findings are consistent with other studies examining paediatric pain and its treatment (Harrison et al. 2014, Shum et al. 2012, Stevens et al. 2014). The generalisability of this study is limited by the conduct of this study in one CCC in a particular hospital setting. Nonetheless this study informs the local setting of paediatric oncology care. Currently no studies exist that have examined the pain-related care provided to paediatric oncology in-patients within an Australian context. Furthermore, the findings may be useful to nurses practicing in paediatric oncology settings internationally. The Quality Score Card was designed by the first author (KP) and has not previously been validated in clinical research. With the absence of a validated audit tool for the assessment and management of pain in children with cancer, the Quality Score Card was based on the recommendations for high quality cancer and paediatric pain-related care available at the time of the study.

CONCLUSIONS

This study indicates that the current documented practices in a paediatric CCC do not fully reflect the recommendations of contemporary paediatric pain management (Gordon et al. 2005, World Health Organization 2012). Children were provided with limited opportunities to make their pain highly visible through the consistent documentation of pain and its treatment. Due to these limited opportunities, there is an urgent need for institutional guidelines that outline clear expectations for the assessment of pain in medically unwell children. The PMI was found to be an ineffective method of evaluating the quality of pain management practice due to limitations of pain documentation. Efforts should be directed at obtaining patient reported outcomes from the child and their caregivers to recognise pain and determine the quality of pain management interventions. Further research is needed to investigate the actual pain practices of health care providers in real time and the influence of social and contextual factors on the pain management interventions provided by paediatric oncology health care providers.

RELEVANCE TO CLINICAL PRACTICE

The limited documentation of pain assessment in the setting of widespread opioid and adjuvant medication use in this study raises an important quality issue. Ultimately, children receiving antineoplastic therapy have few options for analgesic therapy due to the side effect profile of paracetamol and non-steroidal anti-inflammatories (Anghelescu & Oakes 2002, World Health Organization 2012). With the middle step of the WHO analgesic ladder abandoned, strong opioids may now be the principal choice for managing pain in children receiving anti-neoplastic treatment (Zernikow et al. 2008).

Although opioids may have been the most appropriate strategy for the management of pain in this cohort, a risk-benefit analysis of providing analgesia to children receiving antineoplastic therapy is recommended in light of the challenges of organ toxicity coupled with concerns such as neuronal apoptosis (DiMaggio et al. 2009, Dong & Anand 2013, Jain et al. 2014, Ward & Loepke 2012, Wilder et al. 2009) and opioid induced hyperalgesia (Anand et al. 2010) in children receiving prolonged management with opioids. Adjuvants with direct analgesic properties were an important component of pain management strategies for these children and appear to be a useful strategy to addressing the issues of unimodal therapy and reliance on strong opioids.

With limitations evident in this study for the pharmacological management of pain due to the toxic effects of antineoplastic therapy, it is timely that non-pharmacological pain management interventions are given greater attention. Non-pharmacological interventions such as sucrose, aromatherapy, breathing, distraction and positioning for comfort have been determined to be safe and effective methods for minimising pain during cancer treatment for children (Jibb et al. 2015). Clinical nurses are perfectly positioned to address the gaps apparent in delivering multimodal pain management by increasing children's access to non-pharmacological pain management interventions.

REFERENCES

- Altekruse S, Kosary C, Krapcho M, Neyman N, Aminou R, Waldron W, Ruhl J, Howlader N, Tatalovich Z, Cho H, Mariotto A, Eisner M, Lewis D, Cronin K, Chen H, Feuer E, Stinchcomb D & Edwards B (2010) SEER Cancer Statistics Review, 1975-2007. National Cancer Institute, Bethesda, MD. Available at: http://seer.cancer.gov/csr/1975_2007 (accessed July 15th 2014).
- Anand KJ, Willson DF, Berger J, Harrison R, Meert KL, Zimmerman J, Carcillo J, Newth CJ, Prodhon P, Dean JM, Nicholson C, Eunice Kennedy Shriver National Institute of Child Health & Human Development Collaborative Pediatric Critical Care Research Network (2010): Tolerance and withdrawal from prolonged opioid use in critically ill children. *Pediatrics* **125**, e1208-1225.
- Anghelescu D & Oakes L (2002): Working toward better cancer pain management for children. *Cancer Practice* **10 Suppl 1**, S52-57.
- Arend D (2010) Minitab 16 Statistical Software, 16 edn. Minitab Inc, State College, PA.
- Birnie KA, Chambers CT, Fernandez CV, Forgeron PA, Latimer MA, McGrath PJ, Cummings EA & Finley GA (2014): Hospitalized children continue to report undertreated and preventable pain. *Pain research & management*.
- Byrne A, Morton J & Salmon P (2001): Defending against patients' pain: a qualitative analysis of nurses' responses to children's postoperative pain. *Journal of Psychosomatic Research* **50**, 69-76.
- Cleeland CS, Gonin R, Baez L, Loehrer P & Pandya KJ (1997): Pain and Treatment of Pain in Minority Outpatient Pain Study. *Annals of Internal Medicine* **127**, 813-816.
- Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA & Pandya KJ (1994): Pain and Its Treatment in Outpatients with Metastatic Cancer. *New England Journal of Medicine* **330**, 592-596.
- Craig KD (2009): The social communication model of pain. *Canadian Psychology* **50**, 22-32.
- DiMaggio C, Sun LS, Kakavouli A, Byrne MW & Li G (2009): A retrospective cohort study of the association of anesthesia and hernia repair surgery with behavioral and developmental disorders in young children. *Journal of Neurosurgical Anesthesiology* **21**, 286-291.
- Dong C & Anand KJ (2013): Developmental neurotoxicity of ketamine in pediatric clinical use. *Toxicology Letters* **220**, 53-60.

- Donnelly LF, Gessner KE, Dickerson JM, Koch BL, Towbin AJ, Lehkamp TW, Moskovitz J, Brody AS, Dumoulin CL & Jones BV (2010): Quality initiatives: department scorecard: a tool to help drive imaging care delivery performance. *Radiographics* **30**, 2029-2038.
- Ellis JA, McCarthy P, Hershon L, Horlin R, Rattray M & Tierney S (2003): Pain practices: a cross-Canada survey of pediatric oncology centers. *Journal of Pediatric Oncology Nursing* **20**, 26-35.
- Finley GA, Forgeron P & Arnaout M (2008): Action research: developing a pediatric cancer pain program in Jordan. *Journal of Pain and Symptom Management* **35**, 447-454.
- Forgeron PA, Finley GA & Arnaout M (2006): Pediatric pain prevalence and parents' attitudes at a cancer hospital in Jordan. *Journal of Pain and Symptom Management* **31**, 440-448.
- Gordon DB, Dahl JL, Miaskowski C, McCarberg B, Todd KH, Paice JA, Lipman AG, Bookbinder M, Sanders SH, Turk DC, Carr DB, Gordon DB, Dahl JL, Miaskowski C, McCarberg B, Todd KH, Paice JA, Lipman AG, Bookbinder M, Sanders SH, Turk DC & Carr DB (2005): American pain society recommendations for improving the quality of acute and cancer pain management: American Pain Society Quality of Care Task Force. *Archives of Internal Medicine* **165**, 1574-1580.
- Groenewald CB, Rabbitts JA, Schroeder DR & Harrison TE (2012): Prevalence of moderate-severe pain in hospitalized children. *Paediatric Anaesthesia* **22**, 661-668.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N & Conde JG (2009): Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* **42**, 377-381.
- Harrison D, Joly C, Chretien C, Cochrane S, Ellis J, Lamontagne C & Vaillancourt R (2014): Pain prevalence in a pediatric hospital: raising awareness during pain awareness week. *Pain research & management* **19**, e24-30.
- Jain G, Mahendra V, Singhal S, Dzara K, Pilla TR, Manworren R & Kaye AD (2014): Long-term neuropsychological effects of opioid use in children: a descriptive literature review. *Pain Physician* **17**, 109-118.
- Jibb LA, Nathan PC, Stevens BJ, Seto E, Cafazzo JA, Stephens N, Yohannes L & Stinson JN (2015): Psychological and Physical Interventions for the Management of Cancer-

- Related Pain in Pediatric and Young Adult Patients: An Integrative Review. *Oncology Nursing Forum* **42**, E339-357.
- Kestler SA & LoBiondo-Wood G (2012): Review of Symptom Experiences in Children and Adolescents With Cancer. *Cancer Nursing* **35**, E31-E49
10.1097/NCC.1090b1013e3182207a3182202a.
- Kozlowski LJ, Kost-Byerly S, Colantuoni E, Thompson CB, Vasquenza KJ, Rothman SK, Billett C, White ED, Yaster M & Monitto CL (2014): Pain prevalence, intensity, assessment and management in a hospitalized pediatric population. *Pain Management Nursing* **15**, 22-35.
- Larue F, Colleau SM, Brasseur L & Cleeland CS (1995): Multicentre study of cancer pain and its treatment in France. *British Medical Journal* **v310**, p1034(1034).
- Ljungman G, Kreuger A, Gordh T, Berg T, Sorensen S & Rawal N (1996): Treatment of pain in pediatric oncology: a Swedish nationwide survey. *Pain* **68**, 385-394.
- Lu Q, Krull KR, Leisenring W, Owen JE, Kawashima T, Tsao JCI, Zebrack B, Mertens A, Armstrong GT, Stovall M, Robison LL & Zeltzer LK (2011): Pain in long-term adult survivors of childhood cancers and their siblings: A report from the Childhood Cancer Survivor Study. *Pain* **152**, 2616-2624.
- Macintyre P, Scott D, Schug S, Visser E & Walker S (2010) *Acute Pain Management: Scientific Evidence*, 3rd edn. Australian New Zealand College of Anaesthetists and Faculty of Pain Medicine, Melbourne.
- Mattsson JY, Forsner M & Arman M (2011): Uncovering pain in critically ill non-verbal children: nurses' clinical experiences in the paediatric intensive care unit. *J Child Health Care* **15**, 187-198.
- McCarthy M, Glick R, Green J, Plummer K, Peters K, Johnsey L & Deluca C (2013): *Comfort First: an evaluation of a procedural pain management programme for children with cancer*. *Psycho-Oncology* **22**, 775-782.
- 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 CL, Walker L, Weisman S, White RE, Zajicek A, Zeltzer L & PedImpact (2008): Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. *Journal of Pain* **9**, 771-783.

- Miller E, Jacob E & Hockenberry MJ (2011): Nausea, pain, fatigue, and multiple symptoms in hospitalized children with cancer. *Oncology Nursing Forum* **38**, E382-E393.
- Oakes LL, Anghelescu DL, Windsor KB, Barnhill PD & Faughnan LG (2011): An Update: Institutional Quality Improvement Initiative for Pain Management for Pediatric Cancer Inpatients, 2007-2010. *Journal of Pain and Symptom Management*.
- Schiavenato M & Craig KD (2010): Pain assessment as a social transaction: Beyond the "gold standard". *Clinical Journal of Pain* **26**, 667-676.
- Shrestha-Ranjit JM & Manias E (2010): Pain assessment and management practices in children following surgery of the lower limb. *Journal of Clinical Nursing* **19**, 118-128.
- Shum S, Lim J, Page T, Lamb E, Gow J, Ansermino JM & Lauder G (2012): An audit of pain management following pediatric day surgery at British Columbia Children's Hospital. *Pain Research & Management : The Journal of the Canadian Pain Society* **17**, 328-334.
- Stevens BJ, Yamada J, Estabrooks CA, Stinson J, Campbell F, Scott SD, Cummings G & Pain CTiCs (2014): Pain in hospitalized children: Effect of a multidimensional knowledge translation strategy on pain process and clinical outcomes. *Pain* **155**, 60-68.
- Stinson JN, Kavanagh T, Yamada J, Gill N & Stevens B (2006): Systematic review of the psychometric properties, interpretability and feasibility of self-report pain intensity measures for use in clinical trials in children and adolescents. *Pain* **125**, 143-157.
- Strohbuecker B, Mayer H, Evers GCM & Sabatowski R (2005): Pain Prevalence in Hospitalized Patients in a German University Teaching Hospital. *Journal of Pain and Symptom Management* **29**, 498-506.
- Taylor E, Boyer K & Campbell F (2008): Pain in hospitalized children: A prospective cross sectional survey of pain prevalence, intensity, assessment and management in a Canadian pediatric teaching hospital. *Pain research & management* **13**, 25-32.
- Tomlinson D, von Baeyer CL, Stinson JN & Sung L (2010): A systematic review of faces scales for the self-report of pain intensity in children. *Pediatrics* **126**, e1168-1198.
- Treadwell MJ, Franck LS & Vichinsky E (2002): Using quality improvement strategies to enhance pediatric pain assessment. *International Journal for Quality in Health Care* **14**, 39-47.
- Twycross A (2007): Children's nurses' post-operative pain management practices: an observational study. *International Journal of Nursing Studies* **44**, 869-881.

- Twycross A & Collis S (2013): How well is acute pain in children managed? A snapshot in one English hospital. *Pain Management Nursing* **14**, e204-215.
- Twycross A, Parker R, Williams A & Gibson F (2015): Cancer-Related Pain and Pain Management: Sources, Prevalence, and the Experiences of Children and Parents. *Journal of Pediatric Oncology Nursing*.
- Van Cleve L, Muñoz CE, Savedra M, Riggs M, Bossert E, Grant M & Adlard K (2012): Symptoms in Children With Advanced Cancer: Child and Nurse Reports. *Cancer Nursing* **35**, 115-125 110.1097/NCC.1090b1013e31821aedba.
- van Dijk M & Tibboel D (2012): Update on pain assessment in sick neonates and infants. *Pediatric Clinics of North America* **59**, 1167-1181.
- von Baeyer CL & Spagrud LJ (2007): Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. *Pain* **127**, 140-150.
- Ward CG & Loepke AW (2012): Anesthetics and sedatives: toxic or protective for the developing brain? *Pharmacological Research* **65**, 271-274.
- Wilder RT, Flick RP, Sprung J, Katusic SK, Barbaresi WJ, Mickelson C, Gleich SJ, Schroeder DR, Weaver AL & Warner DO (2009): Early exposure to anesthesia and learning disabilities in a population-based birth cohort. *Anesthesiology* **110**, 796-804.
- Williams PD, Williams AR, Kelly KP, Dobos C, Giesecking A, Connor R, Ridder L, Potter N & Del Favero D (2012): A symptom checklist for children with cancer: the therapy-related symptom checklist -- children. *Cancer Nursing* **35**, 89-98.
- Wolfe J, Orellana L, Ullrich C, Cook EF, Kang TI, Rosenberg A, Geyer R, Feudtner C & Dussel V (2015): Symptoms and Distress in Children With Advanced Cancer: Prospective Patient-Reported Outcomes From the PediQUEST Study. *Journal of Clinical Oncology* **33**, 1928-1935.
- World Health Organization (1998) *Cancer Pain Relief and Palliative Care in Children*. World Health Organization, England.
- World Health Organization (2012) *Persisting pain in children package: WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses*. WHO, Geneva. Available at: www.who.com (accessed October 9 2014).
- Zernikow B, Hasan C, Hechler T, Huebner B, Gordon D & Michel E (2008): Stop the pain! A nation-wide quality improvement programme in paediatric oncology pain control. *European Journal of Pain (London, England)* **12**, 819-833.
- Zernikow B, Smale H, Michel E, Hasan C, Jorch N & Andler W (2006): Paediatric cancer pain management using the WHO analgesic ladder--results of a prospective analysis

from 2265 treatment days during a quality improvement study. *European Journal of Pain* (London, England) **10**, 587-595.

Zhu LM, Stinson J, Palozzi L, Weingarten K, Hogan ME, Duong S, Carbajal R, Campbell FA & Taddio A (2012): Improvements in pain outcomes in a Canadian pediatric teaching hospital following implementation of a multifaceted knowledge translation initiative. *Pain research & management* **17**, 173-179.

FIGURE 1

Figure 1. Flow chart of the data collection process

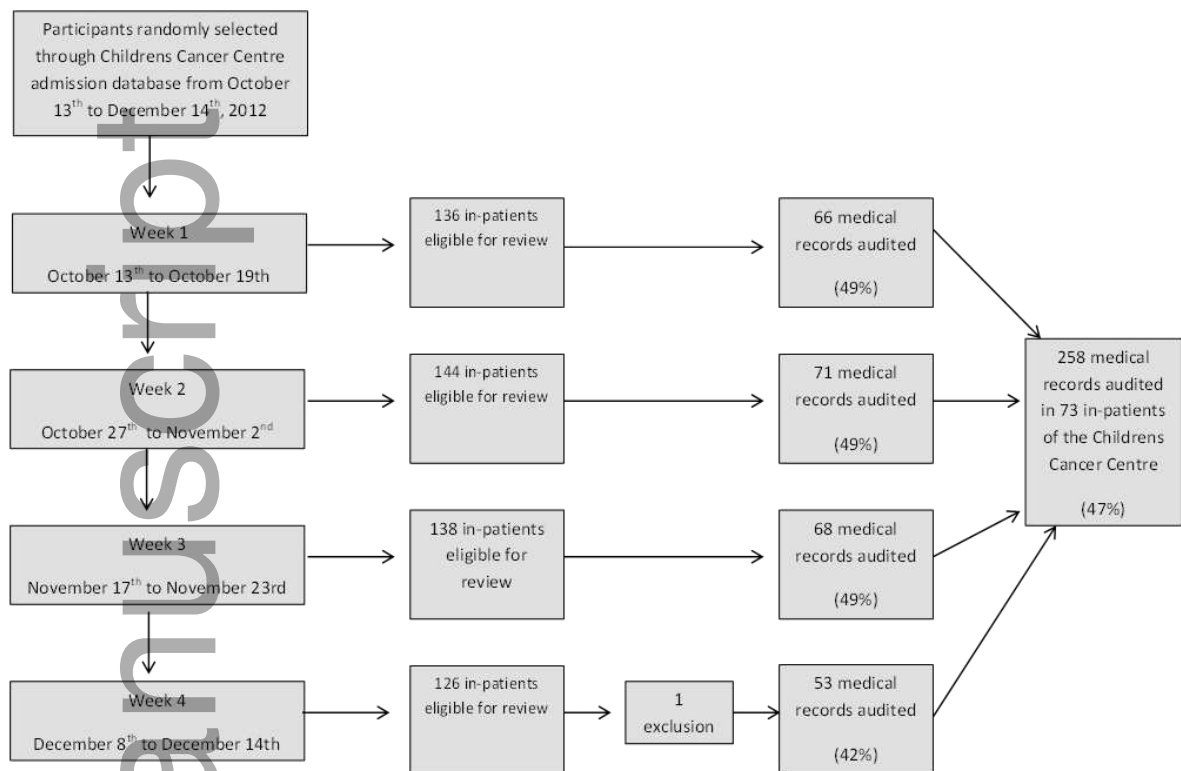


FIGURE 2

Figure 2. Single or combined drug therapies administered

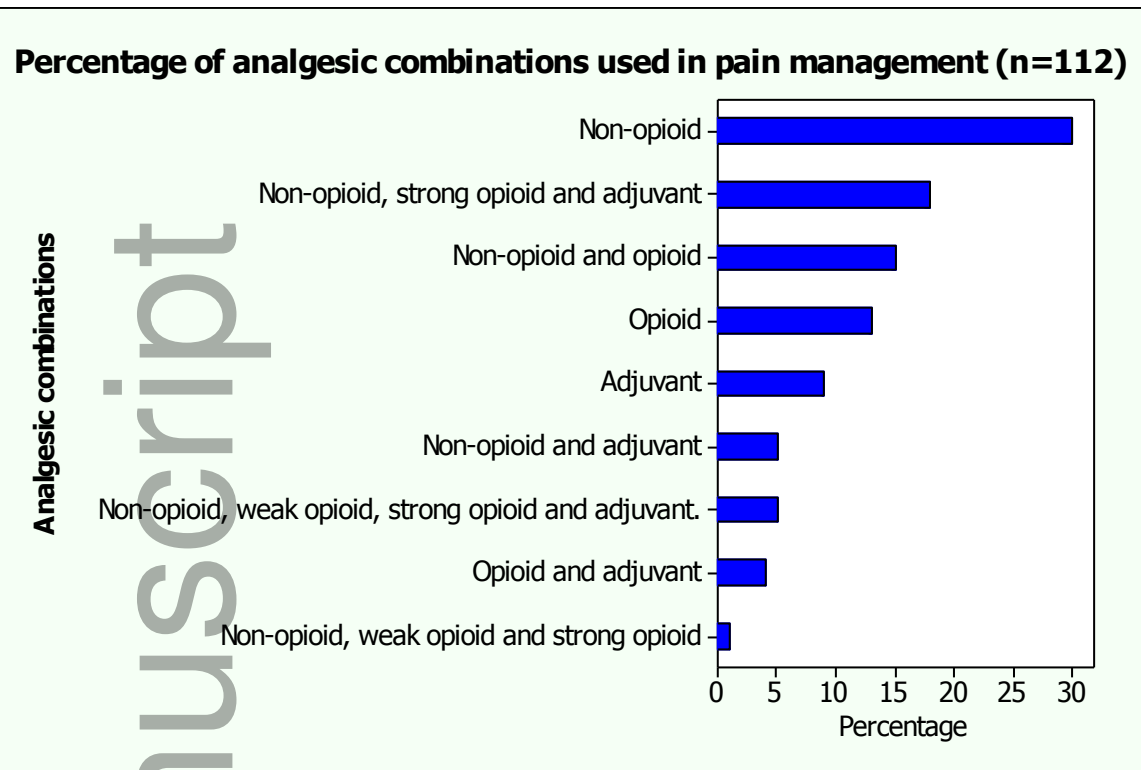


TABLE 1

Table 1
Audit tool domains

Domain	Audit tool measurement
Patient demographics	Date of birth, gender, diagnosis, date of diagnosis, date of admission and surgical procedure during audit period
Pain assessment	Information about pain documented on the observation chart, number of documented pain assessments, minimum and maximum pain-scores, number of sedation scores, number of functional pain assessments (pain at rest & movement), type of pain tool used documented and pain reassessed within 1 hour of pain relieving interventions.
Pain management	Number of analgesic therapies prescribed and administered, number of analgesics prescribed that are scheduled versus non-scheduled, incidence of nurse initiated and once only analgesic administration, management of pain according to the World Health Organisation's analgesic ladder, exclusion of intramuscular injections for delivery of analgesics and non-pharmacological interventions documented.
Pain documentation	Information about patient's pain documented in a highly visible manner on the observation chart and characteristics of pain assessment in the in-patient charts.
Monitoring of processes and outcomes of pain management	Number of sedation scores ≥ 2 , type of adverse event, laxatives prescribed if receiving opioids, percentage of documented pain intensity ≥ 4 (moderate pain) and ≥ 7 (severe pain) in previous 24 hours, change in pain management plan if pain intensity $\geq 7/10$ (severe).
Interdisciplinary care	Frequency and type of documentation about pain by health professionals, pain management planning, incidence of medical reviews due to pain and the involvement of specialist pain management services.
Efficacy of pain management practices.	The Pain Management Index (PMI)

TABLE 2

Table 2
Sample characteristics (N=258)

Sample characteristics	<i>n (%)</i>
Age	
< 1 years	25 (10)
1-3 years	94 (36)
4-7 years	56 (22)
8-12 years	55 (21)
13-18 years	28 (11)
Gender	
Male	152 (59)
Female	106 (41)
Cancer diagnosis	
Blood	127 (49)
Solid	73 (28)
Brain	21 (8)
Non-malignant	37 (15)

Reason for admission		
Medical therapy		198 (77)
Complication associated with treatment		50 (19)
Surgical therapy		10 (4)
Length of stay		
0-30 days		184 (71)
31-100 days		43 (17)
>101 days		31 (12)
Surgical procedure during the EPOC		
Yes		14 (5)
No		244 (95%)

TABLE 3

Table 3

Frequency of documented pain assessments (N=146)

Frequency of pain assessments in 24 hour period	<i>n (%)</i>
Number of pain assessments	
0	71 (49)
1-3	59 (40)
4-6	12 (8)
7-12	4 (3)

TABLE 4

Table 4

Distribution of the documented non-pharmacological pain management interventions (N=44)

Non-pharmacological pain management	<i>n (%)</i>
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intervention	
Barrier cream	21 (47)
Procedural pain clinician*	6 (14)
Distraction	5 (11)
Ice	3 (7)
Sucrose	3 (7)
Salt bath	2 (5)
Buzzy™*	2 (5)
Teething gel	1 (2)
Heat	1 (2)

* Procedural pain clinicians are allied health care professional who work with children and their family to minimise pain and distress associated with medical procedures.

* Buzzy™ is a device that is used in procedural pain management to decrease sharp pain

TABLE 5

Table 5

Distribution of the documented narratives about pain by health professionals (N=319)

Characteristic of pain	Documented narrative	<i>n (%)</i>
Sensory	location	78 (24.5)
	intensity	75 (23.5)

	cause	50 (15.7)
	duration	3 (0.9)
	quality	1 (0.3)
Behavioural	Effect on behaviour	18 (5.7)
	Effect on mood	6 (1.9)
	Effect on function	3 (0.9)
Treatment	Response to intervention	46 (14.4)
	Absence of pain	20 (6.3)
	Treatment given	19 (5.6)

TABLE 6

Table 6

Distribution of the Pain Management Index

Pain Management Index	Total (N=76)	<i>n (%)</i>
-2	4 (5)	
-1	8 (11)	
0	12 (16)	
1	22 (29)	
2	12(16)	
3	18 (24)	