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# **An integrative review of interventions to support parents when managing their child's pain at home**

## **Short title**

Interventions to support parents managing their child's pain at home

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Systematic review

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## **Highlights**

- By targeting parents directly, nurses will be most effective at reducing child pain.
- Parent / nurse-parent interventions are most effective at increasing analgesic administration.
- Nurses can help parents manage child pain at home by providing analgesics of adequate strength.
- Effective interventions are likely to be complex interventions which can be tailored to the child.
- Intervention studies should include measures of adherence, pain behaviour and sedation.

## **An integrative review of interventions to support parents when managing their child's pain at home**

### **Abstract**

*Objectives:* To identify interventions aimed at helping parents manage their child's pain at home and to establish which aspects of interventions were effective.

*Design:* Integrative narrative review.

*Data sources:* MEDLINE, CINAHL Plus, PsychINFO, PsychArticles, AMED, PubMed, Scopus and Web of Knowledge were searched in 2016.

*Review methods:* This narrative synthesis followed Centre for Reviews and Dissemination (2008), and Economic and Social Research Council guidance (Popay et al., 2006). Reasons attributed to intervention success were analyzed using content analysis.

*Results:* From 2,534 papers, 17 were included. A majority were randomized controlled trials (n=13) and most addressed postoperative pain (n=15). A range of interventions were found which targeted parents directly, child-parent interactions and healthcare professional-parent interactions as well as complex interventions. Three studies were successful in reducing child pain at home and seven in increasing appropriate analgesic drug administration. Analysis of reasons attributed to interventions success revealed characteristics of interventions, components of parental pain management, and key features of research which aid researchers in designing and evaluating interventions. Risk of bias was present due to inadequate randomization, lack of a control group and underpowered studies.

*Conclusion:* Nurses should be aware that targeting parents directly is the most effective way of reducing child pain at home. Nurses need to advocate for effective analgesics for their child patients as the ineffectiveness of many interventions was attributed to inadequate analgesic drugs. Once this is achieved success in increasing analgesic drug administration is most likely reached via parent-targeted interventions and those targeting healthcare professional-parent interactions. Successful interventions will be tailored to the child, and adequately powered. Including a measure of sedation will ensure sedation is not mistaken for analgesic effectiveness. Interventions should address multiple facets of pain management and include a measure of pain over a period as opposed to a snapshot in time.

# **An integrative review of interventions to support parents when managing their child's pain at home**

## **MeSH terms**

Child; Pain; Parents; Pain Management; Review; Caregivers

## **Introduction**

Children experience pain as a result of clinical conditions such as sickle cell disease (Zempsky et al., 2017), cancer (Twycross, Parker, Williams, & Gibson, 2015), recurrent abdominal pain (Robins, Smith, Glutting, & Bishop, 2005), migraines (Stubberud, Varkey, McCrory, Pedersen, & Linde, 2016), neuropathic pain (Howard, Wiener, & Walker, 2014), neonatal pain (Valeri, Holsti, & Linhares, 2015), pain resulting from trauma or injury (Stang, Hartling, Fera, Johnson, & Ali, 2014), and surgery (Shum et al., 2012). Pain produces a biological stress response (Brummelte et al., 2015) which has short-term negative consequences such as immune suppression (Huth, Broome, Mussatto, & Morgan, 2003), reduced ability to eat, sleep and interact (Berger, Shuster, & Roenn, 2007), and long-term negative consequences such as increased pain sensitivity (Walker 2017).

Children now spend less time in hospital and more time recovering at home (Fortier, Sender, & Kain, 2011; MacLaren Chorney, Twycross, Mifflin, & Archibald, 2014; Twycross & Collis, 2013; Twycross et al., 2015). While this change in treatment location improves quality of life, if the child is in pain, responsibility for pain management shifts from nurses, to parents. Parents may not have the knowledge and skills required for their pain management role (Vincent, Wilkie, & Szalacha, 2010). Parents of children undergoing surgical procedures often do not give their child sufficient analgesic drugs postoperatively even when they receive instructions about how to do so (Kankkunen et al., 2009). Many parents find pain management challenging, and lack confidence (Kankkunen, Vehviläinen-Julkunen, Pietilä, Kokki, & Halonen, 2003). Some parents lack knowledge (Twycross & Collis, 2013), others have attitudinal barriers such as fear of side-effects and the addiction potential of analgesic drugs (Sutters et al., 2012; Zisk, Fortier, Chorney, Perret, & Kain, 2010). Many parents do not administer analgesic drugs despite recognition of their child's pain (Twycross et al., 2015).

## **Background**

The change in treatment location from hospital, to home, is coupled with an increasing need to support parents in pain management and address their challenges, misconceptions and attitudinal barriers (Fortier et al., 2011). Many authors have called for interventions aimed at supporting parental pain management at home in line with the change in healthcare location (Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011; Fortier et al., 2011; Lu et al., 2011; Twycross et al., 2015). Interventions are required to support parents managing their child's pain and increase their administration of analgesic drugs to ensure children receive sufficient doses.

Intervention development includes design, piloting, evaluation, reporting and implementation stages (Craig et al., 2008). Intervention research is costly to fund and each stage requires careful planning to overcome practical and methodological challenges (Melnyk & Morrison-Beedy, 2012). Learning from both successful and non-successful interventions will provide guidance for future interventions which will increase their success in reducing child pain. There is a need to identify the most effective interventions and ascertain which aspects of interventions make them most effective (Owen et al., 2012).

A recent review of postoperative literature considered interventions aimed at supporting parents managing their child's pain at home (MacLaren Chorney et al., 2014). Eight studies were reviewed. The age range of children in these studies was 1- 18 years with most studies on children aged 3-12 years. Types of surgeries included tonsillectomy with/without associated procedures, mixed day surgery and surgeries requiring hospitalization. Gender was not examined. Overall studies produced small to moderate effect sizes (small effect size <0.2, medium effect size 0.5). MacLaren Chorney and colleagues concluded that future research was needed to better understand factors which contributed to parental postoperative pain management at home.

This current review is the first to expand inclusion criteria to include interventions aimed at supporting parents managing pain caused by any acute or long-term condition at home. This expansion enabled further consideration of the reasons for the effectiveness or non-effectiveness of interventions to support parents in managing their child's pain at home. Literature in this area utilizes a diverse range

of research designs. Integrative review methods were utilized to provide a distinct, systematic approach to literature reviews (Whittemore & Knafl, 2005). The inclusion of different methodologies using narrative description (Bowman, 2007) increased the completeness of the dataset presented (Whittemore & Knafl, 2005).

### ***Objectives***

1. To identify interventions aimed at helping parents manage their child's pain at home.
2. To ascertain which aspects of interventions make them effective or non-effective.

### **Methods**

#### ***Design***

Guidance documents for undertaking reviews in health care from the Centre for Reviews and Dissemination (Akers, Aguiar-Ibáñez, Baba-Akbari Sari, et al., 2009) and ESRC's guidance on narrative synthesis for systematic reviews (Popay et al., 2006) were followed.

#### ***Eligibility criteria***

Effectiveness of pain management was assessed based on two outcome measures: reduction in child pain, and increase in analgesic drug administration. Eligibility criteria according to Population, Intervention, Comparison, Outcome, Time (PICOT) criteria (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) were identified as detailed in Table 1. Literature reviews and grey literature including non-empirical publications, policy and opinion papers were excluded.

#### ***Data sources and study selection***

MEDLINE; CINAHL Plus; PsychINFO; PsychArticles; AMED; PubMed; Scopus; Web of Knowledge databases were searched from database inception (1879, 1961, 1967, 1988, 1985, 1966, 2004, and 1900 respectively) to 26<sup>th</sup> May 2016. Authors of potentially useful papers were contacted if the full paper could not be obtained. Figure 1 presents the selection process. Paper selection followed the Centre for Reviews and Dissemination (CRD) guidance (Akers et al., 2009). The reference lists of literature reviews revealed by the search and included articles, were searched to identify further studies.

### ***Search strategy***

The following search terms were used: child\* OR pediatric OR paediatric OR adolescen\* OR young adult\* OR teenage\*, AND parent\* OR caregiver\* OR guardian\* OR famil\*, AND pain management, NOT PICU or “paediatric intensive care” OR “pediatric intensive care” OR death OR dying OR bereave OR “painful procedures” OR immunisation OR immunization OR inject\* OR pregan\* OR labour OR labor. Where available, the following limits were applied: English language publications, publications relating to humans, and publications relating to children (under age 18). The search strategy, was developed iteratively (Teddlie & Tashakkori, 2009) with the aim of providing the broadest possible search to reduce the risk of missing articles. Limiters and the Boolean operator ‘NOT’ was used to reduce the number of irrelevant articles retrieved by the search.

### ***Data collection process***

The following items were extracted from each study: aims, design, participants (number), participants (condition), intervention, intervention details, comparison, outcome measures, measure of child pain, duration of follow up, success in reducing child pain, success in increasing analgesic drug administration, success in other outcome measures, conclusions, reasons attributed to success / failure of intervention, comments. Items of data collection were chosen based on CONSORT guidelines combined with the relevance to the review aim (Moher, Liberati, Tetzlaff, & Altman, 2009; Schulz, Altman, & Moher, 2010). Principle summary measures were: reduced child pain; increased analgesic drug administration; and reasons attributed to intervention success or failure. Success was judged on statistical significance. Outcomes of all other measures were collected regardless of significance. Non-significant outcomes were reported as such.

### ***Review methods and analysis***

When deciding whether to conduct a meta-analysis, an assessment was made of the homogeneity of the data in terms of participants, interventions and outcomes (Haidich, 2010; Russo, 2007) with reference to the research question (Borenstein et al., 2009). Many, but not all, interventions targeted children postoperatively which meant that a meta-analysis including these studies may have been possible had there been homogeneity in intervention and outcomes. Interventions differed in terms of

their target, mechanism, and resources. A variety of different scales and methods were used to measure key outcomes. Due to this diversity, meta-analysis was not possible and a narrative synthesis was conducted following guidance from the ESRC methods program (Popay et al., 2006) and the Centre for Reviews and Dissemination (Akers et al., 2009). Included papers were uploaded to NVivo™ (Version 10, QSR International) to aid review. Using methods content analysis, reasons authors of the studies attributed to the success of interventions were analyzed (Hsieh & Shannon, 2005). Text relating to reasons which authors of each study attributed to the relative success of their intervention were extracted and uploaded to NVivo™ (Version 10, QSR International). One author (RP) read and re-read the text to get a sense of the whole, codes were derived and sorted into categories and eventually subcategories. Finally, exemplars for each subcategory were sought.

### **Reliability and validity**

#### ***Appraisal of rigor in individual studies***

A structured risk of bias assessment was conducted on individual studies and used to weight the narrative synthesis by putting more emphasis on studies with minimal risk of bias (Akers et al., 2009).. Thirteen randomized controlled trials (RCTs) were assessed using Critical Appraisal Skills Program tool for RCTs (Singh, 2013). The remainder were assessed using Caldwell et al.'s framework (Caldwell, Henshaw, & Taylor, 2011) which includes a standard set of criteria as well as specific criteria for qualitative or quantitative research. The purpose of this framework is not to score each study but to highlight the strengths and weaknesses of each study to enable appraisers to weight the studies in the synthesis.

#### ***Risk of bias across studies***

The heterogeneity of studies meant it was not possible to construct a funnel plot to statistically ascertain publication bias. Instead the implications of not including potentially useful papers for which the full paper could not be obtained was considered (Liberati et al., 2009). A search was conducted for follow-up studies to included studies which described themselves as feasibility or pilot studies to ascertain whether such studies had been conducted but either not published or missed in the search. The significance of studies included was examined to ascertain whether there may be studies which had been conducted but not published due to lack of significance.



## Results

Seventeen papers were selected (Figure 1). Study characteristics are presented in Table 2. Thirteen studies were RCTs, three were other quantitative designs and one was mixed-methods. Fifteen addressed post-operative pain, one migraine pain and one chronic idiopathic pain. Eight used standard care as a control group, two had no control group. Median follow-up was 4 days (interquartile range: 3-109). Median sample size was 70 (interquartile range: 47-108). The most common location of study was United States (n=7), two were conducted in Australia, Canada, the UK, and Finland, one in Iceland, and Denmark.

### *Descriptive summary*

*Parent-targeted interventions* Three studies (all RCTs addressing postoperative pain) used around-the-clock (ATC) interventions which encourage parents to administer analgesic drugs regularly as opposed to when required (Sutters et al., 2004, 2010; Wiggins, 2009). Both studies by Sutters and colleagues had three groups: "ATC", "ATC plus nurse coaching" and "standard care" (Sutters et al., 2004, 2010). Nurse coaching was provided to parents both in hospital, and at home via follow-up phone calls. Both studies found no differences between "ATC" and "ATC plus nurse coaching" groups so these groups were combined into one intervention group for analysis. In 2004, Sutters and colleagues found that, despite receiving statistically significantly more analgesic medications, children in the intervention groups did not demonstrate a statistically significant reduction in pain scores due to inadequate strength of the analgesic drug administered (acetaminophen with codeine). Sutters and colleagues duplicated this study in 2010 with acetaminophen and hydrocodone. Compared to controls, the intervention group demonstrated a statistically significant reduction in pain scores at various specific time points. Mean differences in pain scores on the numeric rating scale (NRS) from 0 (no pain) to 10 (worst pain imaginable) were at rest on second evening 1.1 (p=0.028), second morning 1.8 (p=0.002), with swallowing on first morning 1.1 (p=0.037), second evening 1.1 (p=0.043), second morning, 1.7 (p=0.003) and third evening 1.3 (p=0.011) (Sutters et al., 2010). In 2009, Wiggins found the ATC intervention did not significantly reduce pain despite significantly increasing analgesic drug administration by day two (range 4-6 doses for intervention, 1-4 doses for control;

p=0.014). Analgesic drugs for this study included: acetaminophen and codeine; acetaminophen and hydrocodone; and acetaminophen and oxycodone.

Five studies used parental education interventions (Allen & Shriver, 1998; Bailey, Sun, Courtney, & Murphy, 2015; Chambers et al., 1997; Helgadóttir & Wilson, 2014; Vincent et al., 2012). Vincent and colleagues did a quasi-experimental study (Vincent et al., 2012), the remainder were RCTs. Allen and Shriver addressed migraine pain (Allen & Shriver, 1998), the remainder addressed postoperative pain. Three studies involved provision of both written and verbal information (Allen & Shriver, 1998; Helgadóttir & Wilson, 2014; Vincent et al., 2012), the remainder provided written information only (Bailey et al., 2015; Chambers et al., 1997). Allen and Shriver combined biofeedback with parental education finding significant pain reduction (mean difference 1.4;  $p \leq 0.05$ ) and increased adaptive functioning as measured by the Parent Perception of Pain Interference Questionnaire (Kerns, Turk, & Rudy, 1985) (mean difference 16,  $p \leq 0.05$ ) compared to a control group receiving biofeedback alone (Allen & Shriver, 1998). Chambers and colleagues' pain education booklet significantly altered attitudes (mean = 5.33 [pain education], 4.82 [assessment control], 4.76 [no pain education];  $p < 0.01$ ), and increased analgesic drug administration only on day three (mean = 0.8 [pain education group], 0.2 [assessment control and no pain education groups];  $p < 0.05$ ) but did not significantly reduce child pain (Chambers et al., 1997). Vincent and colleagues reported no significance in pain reduction or analgesic drug administration although there was a significant increase in child satisfaction ( $\chi^2=4.90$ ,  $p=0.03$ ) (Vincent et al., 2012). Helgadóttir and Wilson found statistically significant lower pain behavior when distraction and pain management education was provided to parents compared with pain management education alone (repeated measures analysis of covariance,  $p=0.023$ ) (Helgadóttir & Wilson, 2014). Analgesic drug administration was not measured and there was no significant pain reduction. Bailey and colleagues found oxycodone information increased parental satisfaction (mean difference 1.69,  $p < 0.001$ ), knowledge ( $\chi^2=29.53$ ,  $p < 0.001$ ), and significantly reduced pain scores at two of three time points (Day 3: mean difference=1.07,  $p=0.05$ ; Day 7: mean difference=1.55,  $p=0.02$ ) (Bailey et al., 2015).

*Child-parent interaction targeted interventions* Pain assessment tools to help parents manage their child's pain at home following surgery were evaluated in three RCTs (Franck, Allen, & Oulton, 2007;

Kankkunen et al., 2009; Unsworth, Franck, & Choonara, 2007). None found a statistically significant reduction in child pain or increased analgesic drug administration. Unsworth and colleagues provided parents with instructions on the Wong-Baker Faces Pain Scale (WBFPS) (Wong & Baker, 1988) and corresponding analgesic drug administration (Unsworth et al., 2007). These parents were more likely to administer codeine as instructed (24% codeine administration [control], 37% [intervention];  $p=0.004$ ) and less likely to administer unnecessary analgesic drugs (69% [control], 39% [intervention];  $p=0.001$ ). Franck and colleagues found no pain or analgesic administration differences when children were given a temporary tattoo of the WBFPS compared to a control group who received a paper version of the scale (Franck et al., 2007). Kankkunen and colleagues (2009) found no differences in problems faced by parents managing postoperative pain when provided with Parents Postoperative Pain Measure (Chambers, Reid, McGrath, & Finley, 1996).

Using an RCT design, Palermo and colleagues addressed chronic idiopathic pain through family-directed, internet-based, cognitive behavioral therapy (CBT) delivered online (Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009). Child and adult modules covered specific topics and skills such as deep breathing and muscle relaxation. The intervention resulted in significant reductions in activity limitations (mean difference 2.74,  $p=0.004$ ) and pain reductions (mean difference 1.17,  $p=0.03$ ) compared to wait list control. In an RCT addressing postoperative pain, Hegarty and colleagues found administering take-home analgesic drugs did not statistically significantly influence pain, analgesic drug administration, nausea, vomiting or sleep when compared with parent supplied analgesic drugs (Hegarty et al., 2013).

*Nurse-parent interaction targeted interventions* Sepponen and colleagues, provided an education program to doctors and nurses which increased analgesic drugs administered by parents (68% pre-intervention, 80% post-intervention [ $p=0.028$ ]) and influenced analgesic drug choices (ibuprofen use 28% pre-intervention, 52% post-intervention [ $p=0.002$ ]; acetaminophen use 56% pre-intervention, 24% post-intervention [ $p<0.001$ ]), but did not reduce pain (Sepponen, Kokki, & Ahonen, 1999).

Paquette and colleagues found telephone calls by nurses following surgery increased analgesic drug administration, but did not reduce pain (Paquette et al., 2013).

*Complex interventions* Complex interventions were used in two papers which had a combination of techniques for postoperative pain (Sutters et al., 2012; Walther-Larsen et al., 2016). Neither study used a control group. In a mixed-methods study, Sutters and colleagues concluded education on pain assessment, ATC instruction with provision of a timer, written information, follow-up phone calls and nurse coaching reduced pain and increased analgesic drug administration (Sutters et al., 2012). In a prospective observational cohort study, Walther-Larsen and colleagues concluded provision of a pain assessment tool, tailored provision of analgesic drugs, and both written and verbal parental education reduced pain (Walther-Larsen et al., 2016).

### ***Reasons for intervention success or failure***

Table 3 displays the results of the analysis on the reasons authors of the studies attributed to the success or failure of their interventions. Three categories arose: characteristics of interventions; components of parental pain management which were addressed by interventions; and key features of research.

Characteristics identified as contributory to intervention success were grouped into two subcategories: complex interventions and tailored interventions. Seven authors either attributed their interventions' success to the complexity of their intervention where the intervention had addressed more than one aspect of parental pain management, or attributed its failure to their interventions' simplicity (Franck et al., 2007; Hegarty et al., 2013; Kankkunen et al., 2009; Sutters et al., 2010, 2012; Vincent et al., 2012; Walther-Larsen et al., 2016). Complex interventions were evaluated in two studies but as neither study included a control group, the effectiveness of these interventions cannot be assessed. Three authors suggested that tailoring their intervention to the patient and clinical situation, for example the type of surgery, was a key factor in intervention effectiveness (Chambers et al., 1997; Sutters et al., 2010; Walther-Larsen et al., 2016).

Four subcategories of components of parental pain management were identified: analgesic drug effectiveness, pain education, pain assessments, and attitudes. Eight authors attributed the success or failure of their intervention to effective or ineffective analgesic drugs respectively (Bailey et al., 2015; Helgadóttir & Wilson, 2014; Paquette et al., 2013; Sepponen et al., 1999; Sutters et al., 2004,

2010; Walther-Larsen et al., 2016; Wiggins, 2009). Authors recognized intervention success as dependent on the sufficient strength of analgesic drug prescription (Bailey et al., 2015; Helgadóttir & Wilson, 2014; Paquette et al., 2013; Sutters et al., 2004, 2010; Wiggins, 2009). Analgesic drug formulation could also be a barrier to effective interventions (Sepponen et al., 1999). Seven authors attributed parental education to the success or failure of their intervention (Chambers et al., 1997; Sutters et al., 2004, 2010, 2012; Vincent et al., 2012; Walther-Larsen et al., 2016; Wiggins, 2009). Education could be ineffective if the interaction was too brief, but overloading information restricted intervention effectiveness (Vincent et al., 2012). Written information alone could be sufficient (Sutters et al., 2004, 2010) but most effective when tailored to the situation (Chambers et al., 1997). Two authors attributed pain assessment tools to their interventions' success (Chambers et al., 1997; Walther-Larsen et al., 2016). Two authors recognized parental attitudes towards pain management as a barrier to effective interventions (Chambers et al., 1997; Vincent et al., 2012). Parental misconceptions regarding the side-effects, tolerance and addiction potential of analgesic drug may have hindered administration of analgesic drugs (Vincent et al., 2012). Knowledge gaps and misconceptions regarding pain expression may have hindered pain assessment (Chambers et al., 1997).

Four features of research were attributed to intervention effectiveness. Eight authors attributed inadequate sample size to the failure of their intervention (Allen & Shriver, 1998; Franck et al., 2007; Kankkunen et al., 2009; Paquette et al., 2013; Sutters et al., 2010; Unsworth et al., 2007; Vincent et al., 2012; Walther-Larsen et al., 2016). Two authors suggested their interventions may have been ineffective due to non-adherence (Allen & Shriver, 1998; Chambers et al., 1997). Of these, one paper had an indirect measure of adherence and concluded that adherence was not easily achieved (Allen & Shriver, 1998). The use of the internet in the web-based intervention enabled a direct measure of adherence and found that adherence was good overall and was higher for children than parents (Palermo et al., 2009). Due to the variety of interventions, adherence in one intervention could not be used as confirmation of adherence in any other intervention.

One author was able to demonstrate success using a measure of pain behavior which enabled an assessment of pain over a longer period rather than a snapshot in time (Helgadóttir & Wilson, 2014).

Although self-report has historically been considered the gold standard, other individual and contextual factors including pain behavior should be considered in pain assessment (Twycross, Voepel-Lewis, Vincent, Franck, & von Baeyer, 2015). One author suggested a measure of sedation would eliminate the possibility of sedation being mistakenly measured as low pain (Sutters et al., 2012). Two studies assessed sedation as an intervention outcome: in 2010, Sutters and colleagues study found no differences in sedation or pain intensity; in 2012, Sutters and colleagues found a reduction in pain intensity and an increase in sedation. It is possible the reduction in pain intensity found in the 2012 study may have been a product of increased sedation rather than a true pain reduction.

### ***Risk of bias within studies***

Key results from the risk of bias assessment are presented in Table 2. Methodological limitations which incur a risk of bias were present in all studies. Nine studies were underpowered (Allen & Shriver, 1998; Chambers et al., 1997; Franck et al., 2007; Kankkunen et al., 2009; Paquette et al., 2013; Sutters et al., 2010; Unsworth et al., 2007; Vincent et al., 2012; Wiggins, 2009). Five studies reported significant differences between groups pre-intervention (Bailey et al., 2015; Chambers et al., 1997; Franck et al., 2007; Paquette et al., 2013; Sutters et al., 2010). Two studies did not provide information on group homogeneity (Hegarty et al., 2013; Wiggins, 2009). Three studies did not provide information regarding characteristics of participants who withdrew (Hegarty et al., 2013; Kankkunen et al., 2009; Sutters et al., 2004). Two studies did not have a control group (Sutters et al., 2012; Walther-Larsen et al., 2016). Four studies did not use an appropriate method of randomization (Hegarty et al., 2013; Helgadóttir & Wilson, 2014; Kankkunen et al., 2009; Palermo et al., 2009) and three studies did not report how participants were randomized (Allen & Shriver, 1998; Chambers et al., 1997).

### ***Risk of bias across studies***

Two potentially useful papers revealed by the search strategy could not be located. These interventions may have influenced this review but abstracts alone are insufficient to ascertain the extent or direction. Follow-up studies could not be found for three studies described as feasibility or pilot studies (Franck et al., 2007; Sutters et al., 2012; Wiggins, 2009) which suggests follow-up

studies are either unpublished or have not been conducted. Two studies did not report a statistically significant outcome in at least one variable which indicates that there may be a bias against the publication of non-significant studies (Dwan, Gamble, Williamson, & Kirkham, 2013) and there may be interventions which have not been published due to non-significant findings.

## **Discussion**

This review evaluated the effectiveness of interventions to support parents managing their child's pain at home with respect to reducing child pain and increasing analgesic drug administration. Excluding interventions which lacked a control group, parent-targeted interventions constitute the largest category and produced the greatest number of successful interventions for reducing pain. Three of the eight studies in this category (one ATC intervention and two parental education interventions) demonstrated a statistically significant reduction in child pain, albeit only at specific time points. Although interventions in this category show the greatest promise of being successful, this group of interventions produced more interventions which were unsuccessful than interventions which were successful.

Interventions targeting parents directly or those targeting the nurse-parent interaction may be most effective at increasing analgesic drug administration. Six studies including four of the eight parent-targeted interventions (all three ATC and one of the three parental education), and all nurse-parent interaction interventions (the telephone follow-up and the doctor and nurse education), demonstrated statistically significant increases in analgesic drug administration.

Twice as many interventions were successful in increasing analgesic drug administration as interventions successful in reducing child pain which suggests it is easier to increase analgesic drug administration than to reduce pain. One potential explanation is that analgesic drugs administered in many interventions may have been inadequate (Bailey et al., 2015; Helgadóttir & Wilson, 2014; Paquette et al., 2013; Sutters et al., 2004, 2010; Walther-Larsen et al., 2016; Wiggins, 2009). In Sutters and colleagues' two studies (Sutters et al., 2004, 2010) when analgesic drugs were changed from acetaminophen and codeine to acetaminophen and hydrocodone, the intervention became successful in reducing child pain. Recent research has revealed genetic differences in the metabolism

of codeine which means that its analgesic effectiveness has been questioned and since 2013, codeine is no longer recommended for use in children and young people (Department of Health, 2013; Van Hout et al., 2014). Inappropriate use of codeine may have been a factor resulting in the ineffectiveness of interventions included in this review.

Another potential explanation is that studies may not have accurately assessed children's pain. Most studies measured pain intensity on a scale. Three studies included other pain-related measures including satisfaction with pain levels (Vincent et al., 2012), activity limitations (Palermo et al., 2009) and pain behavior (Helgadóttir & Wilson, 2014). In each case, interventions were found to be effective in influencing these pain-related measures. While pain intensity scales provide a snapshot of pain at one moment in time, these alternative measures provided a measure of pain over a longer period and potentially a more accurate assessment of intervention effectiveness.

Seven authors cited the multifaceted nature of interventions as a characteristic responsible for intervention success. Despite lacking a control group, both multifaceted interventions claimed success in reducing child pain. There is growing recognition of the effectiveness of multifaceted interventions (Campbell, Fitzpatrick, Haines, & Kinmonth, 2000). Frameworks exist to guide researchers in their development and evaluation (Campbell & Edwards, 2012; Craig et al., 2008).

Risk of bias within studies was high, primarily due to being underpowered a feature which authors frequently attributed to their interventions' failure. Many studies may not have detected significant differences where they existed (Schulz & Grimes, 2005) which has negative repercussions for this area of research and limits this reviews' support for interventions.

Due to small effect sizes and mixed results, MacLaren Chorney and colleagues similarly did not draw a conclusion as to which type of intervention was preferable for reducing pain (MacLaren Chorney et al., 2014). Regarding analgesic drug administration, they concluded ATC studies to be the most effective with parent education and pain assessment provision regarded as ineffective. While this review is in agreement, it additionally concludes in support of parental education interventions for improving analgesic drug administration. These divergent findings may be resultant from differing



categories for describing interventions or differing inclusion criteria. MacLaren Chorney and colleagues did not group interventions according to the intervention target but considered only the mechanism of the intervention. Their tighter inclusion criteria led to fewer studies being included and a narrower dataset being reviewed.

### ***Limitations***

Six of the 17 studies included had been published more than 10 years ago indicating that many of these interventions need updating in line with treatment advances. The heterogeneity of studies meant meta-analysis was not possible, a robust narrative synthesis was conducted using alternative methods with the same goal: to collate the dataset and draw conclusions (Popay et al., 2006). Narrative synthesis methodology is growing in recognition and has been recommended as an approach to literature reviews even when meta-analysis is possible (Centre for Reviews and Dissemination, 2008).

At an outcome level, assessment of risk of bias identified key areas of concern in all studies. Despite these areas limiting meaningful inferences, awareness of the risk of bias enabled more accurate conclusions to be drawn. At review level, interventions may not have been detected by the literature search due to incomplete retrieval. Limited resources meant grey literature was not searched. Non-English publications were excluded and it was necessary to include Boolean operators and limiters in the search strategy. Many articles were excluded after review of the title. Article titles can be misleading and this step may have meant relevant studies were not selected.

The analysis of the reasons authors attributed to the success or failure of their interventions was conducted by one author (R Parker) using content analysis. Issues of trustworthiness, credibility and the role of researcher bias should be considered when interpreting these findings (Cope, 2014; Noble & Smith, 2015). No attempt was made to establish credibility through techniques such as peer debriefing, triangulation, or negative case analysis (Hsieh & Shannon, 2005). Codes were developed freely from the data using a deductive approach, but this lack of a framework limits the theoretical robustness of the results.

### ***Practice implications***

Nurses should be aware that the ineffectiveness of many interventions was attributed to inadequate analgesics. Nurses need to advocate for effective analgesics tailored to the child and clinical situation such as the type of surgery. Without the provision of adequate analgesics, interventions to support parents in managing their child's pain at home will be futile.

Nurses should be aware that targeting parents directly is the most effective way of reducing child pain at home. Parents could be prepared for managing their child's pain at home by providing appropriate parent education or providing ATC dosing schedules. The nurse education program resulted in increased analgesic administration by parents. Ensuring knowledge of pain and pain management remains up to date, enables nurses to empower parents to give sufficient analgesic doses to their children at home. Nurses may help parents increase their analgesic administration by providing follow-up phone calls. A combination of nurse education alongside providing parents with education, ATC dosing schedules, and follow up phone calls would constitute a complex intervention which several authors considered would be more effective.

Many interventions were delivered in short timeframes reflective of the acute nature of postoperative pain (Bailey et al., 2015). Nurses should be aware that postoperative pain interventions may not be transferable to other pain etiologies.

### ***Research implications***

Researchers designing interventions to assist parents managing their child's pain at home should consider a complex intervention with multiple facets targeting different components of parental pain management. Parent targeted interventions and interventions targeting the healthcare professional-parent interaction are most likely to be successful. It is important that interventions involve a degree of flexibility which allows them to be tailored to the child and the clinical situation.

In the evaluation phase, funders should be aware of the importance of sufficiently powered studies and should fund to enable adequate recruitment. Researchers may consider using a pain measure

such as pain behavior to measure pain over a period as well as pain intensity which measures pain as a snapshot in time which will increase the accuracy of the assessment of the intervention effectiveness. Including a measure of adherence will allow researchers to ascertain whether their intervention is acceptable to children and their families. Including a measure of sedation will allow researchers to ascertain the effectiveness of their intervention and control for any confounding effect that sedation may have on pain reduction.

## Conclusion

This integrative narrative review has identified interventions which aimed to help parents manage their child's pain at home and ascertained which aspects of interventions make them effective.

Interventions which target parents directly were most effective at reducing child pain at home. Many interventions may have been limited in their effectiveness by inefficient analgesic drugs. Once effective analgesic drugs are provided, parent-targeted interventions and those targeting healthcare professional-parent interactions were most effective at increasing analgesic drug administrations.

Characteristics of interventions, components of parental pain management, and key features of research which would increase the effectiveness of interventions were discussed.

## Disclosures

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## Tables

Table 1: Inclusion criteria according to PICOT

Population			Intervention	Comparison	Outcomes			Time
Children	Parents	Cause of pain	Intervention	Comparison	Parental pain management	Pain in children	Home	Timeframe
<p>Studies investigating children from birth to 18 were included.</p> <p>Studies including teenagers and young adults were included where there was evidence which assisted in meeting the objectives.</p>	<p>Studies investigating mothers, fathers, guardians or any individual with primary caregiving responsibility for the child.</p>	<p>Any disease which causes children to be in pain at home.</p> <p>Any medical procedures which cause children to be in pain at home.</p>	<p>Any intervention aimed at reducing children's pain.</p> <p>Intervention could be delivered by any healthcare professional and take place in any location including home and hospital.</p> <p>Any intervention aimed at increasing analgesic administration.</p>	<p>Any comparison will be included.</p>	<p>Any aspect of parental knowledge or attitudes towards pain management.</p> <p>Administration of analgesics or non-drug methods of pain management at home.</p> <p>Other aspects of child pain management by parents at home.</p> <p>Parental assessment of their child's pain at home.</p>	<p>Self-report of pain by children using any pain assessment tool.</p> <p>Proxy-report of pain in children by parents using any pain assessment tool.</p> <p>Surrogate outcomes which have been shown to be indicators of pain (e.g. heart rate) will be included.</p> <p>Non-validated tools will be included.</p>	<p>Any setting in which children's pain management is solely parents' responsibility.</p>	<p>Any duration of data collection will be included.</p>



Table 2: Characteristics of included studies

Author Date Country Design	Participants Condition	Aims	Intervention type Intervention details Comparison	Statistical significance			Conclusions	Key points from risk of bias assessment
				Pain reduction	Analgesic drug administration	Other outcomes		
Sutters et al. 2004 US RCT	Parents of children (n=80). Surgery: ENT	To determine whether ATC dosing, with or without nurse coaching, reduced children's reports of pain intensity, increased pain relief, and analgesic drug consumption.	ATC and nurse coaching 2 intervention groups both receiving digital timer: ATC group and ATC+Nurse coaching group Comparison: standard care	No	Yes (F (2, 77) = 24.55, P<0.001)	No significant difference in nausea and vomiting	Ineffective analgesic drugs meant that the intervention was ineffective. A surprising finding that the nurse coaching group was not significantly different. This is due to effective written instruction.	No demographic details provided of participants who withdrew.
Wiggins et al. 2009 US RCT	Parents of children (n=13). Surgery: ENT	To describe how families implemented an alarm intervention designed to promote postoperative ATC administration of analgesic drugs.	ATC Asked to set an alarm as a reminder to administer prescribed analgesic drug. Comparison: standard care	No	Yes (by day 2) (range 4-6 doses for intervention group, 1-4 doses for control; p=0.014)	No significant difference in fluid intake or sleep	The intervention was ineffective due to heterogeneous and small sample, ineffective analgesic drugs.	Insufficient sample size. No provision of group homogeneity or demographics provided.

Sutters et al. 2010 US RCT	Parents of children (n=113). Surgery: ENT	To determine the effectiveness of ATC analgesic drug administration, with or without nurse coaching, compared to standard care.	ATC and nurse coaching 2 intervention groups both receiving digital timer: ATC group and ATC+Nurse coaching group Comparison: standard care	Yes at specific time points (At rest: second evening t=2.23, p=0.028; second morning t=2.33, p=0.002. With swallowing: first morning t=2.11, p=0.037; second evening t=2.05, p=0.43; second morning t=2.99, p=0.003; third evening t=2.599, p=0.011)	Yes (F(1,102)=49.67, p<0.0001)	No significant difference in sedation, light-headedness, feeling dizzy, nightmares, nausea, vomiting, and constipation.	Effectiveness of intervention attributed to the combination of the specific analgesic drug chosen (acetaminophen with hydrocodone) and ATC dosing. Nurse coaching didn't have any effect so written instructions are sufficient. ATC is appropriate because post-op pain is predictable. Pain intensity only measured twice and fluctuations in intensity not detected.	Insufficient power to detect small effect sizes. Significant differences between groups in mother's ethnicity.
Chambers et al. 1997 Canada RCT	Parents (n=82). Surgery: ENT	To evaluate the effectiveness of a booklet for parents on the assessment and management of children's pain in terms of attitudes, assessment and medication administration.	Parent education Written information. Pain education booklet: "Pain, pain, go away: helping children with pain" Comparison: pain assessment control and no pain education control	No	Yes (only day 3) (mean = 0.8 [pain education group], 0.2 [assessment control group and no pain education group]; p<0.05)	Parental attitudes (mean = 5.33 [pain education group], 4.82 [assessment control group], 4.76 no pain education group; p<0.01)	How parents assess pain and their attitudes toward children's pain medications contribute independently to how they medicate their children's pain. Optimal pain management achieved through targeting parental concerns about pain medications and educating about assessment. Unknown whether parents read the whole book, book was not specific to day surgery.	Randomization procedure is unclear. Slight variances in number and age of children of parents between groups. Small sample size may have prevented detection of small effects.

Allen & Shriver 1998 US RCT	Children (n=27) and their parents. Migraine	To evaluate the efficacy of parent-mediated pain behavior management strategies implemented by parents of children undergoing biofeedback treatment for migraine headache.	Parent education Biofeedback combined with written and verbal information on influence of parental behavior on child pain. Comparison: biofeedback alone.	Yes at 3 months (mean difference 1.4; $p \leq 0.05$ ) but not at 1 year	n/a not assessed	Adaptive functioning (mean difference 16, $p \leq 0.05$ )	Success cannot be attributed to the intervention because there was no measure of adherence to the intervention. Significance only noted over first 3 months. Potentially participants forgot the intervention after that time. As both groups improved, the intervention may have meant participants reached the stage of recovery quicker than the control.	No indication of how randomization was conducted. Small sample size may have prevented small effects to be detected at later time points. Therapist not blinded so potentially doing something additional caused the change.
Vincent et al. 2012 US Quasi-experimental	Children (n=108) and their parents. Surgery: various	To compare the effectiveness of Home Pain Management for Children (HPMC) with usual discharge teaching on children's pain intensity, parents' analgesic drug administration, parents' and children's satisfaction with pain levels, and use of unplanned healthcare.	Parent education Written and verbal information. Pain Management Information sheet and follow up session to discuss sheet. Comparison: standard care	No	No	Child satisfaction ( $\chi^2=4.90$ , $p=0.03$ )	The intervention was ineffective potentially due to: too much written information, insufficient emphasis on the importance of analgesic drugs, parental attitudinal barriers, or small sample sizes.	Insufficient sample size. Sample mostly white children of educated parents.

Helgadottir & Wilson 2014 Iceland RCT	Children (n=93) and their parents. Surgery: ENT	To determine the effectiveness of educating parents to provide distraction in decreasing postoperative pain at home.	Parent education Written and verbal pain management and distraction education. Comparison: written pain management education only.	No	n/a not assessed	Pain behavior (p=0.023; $\eta^2=.076$ )	Pain behavior is an equally important aspect of pain experience as pain intensity. It was measured over a day as opposed to at one moment. Many children had clinically significant pain despite correct analgesic drug administration.	Block randomization is not true randomization.
Bailey et al. 2015 Australia RCT	Parents of children (n=58). Surgery: ENT	To evaluate pediatric post-tonsillectomy pain management using oxycodone when a specific analgesic drug information sheet is provided.	Parent education Written information. Oxycodone information sheet Comparison: standard care	Yes on day 3 (mean difference=1.07, p=0.05) and day 7 (mean difference=1.55, p=0.02), not on day 5	n/a not assessed	Parental satisfaction (mean difference 1.69, p<0.001), parental knowledge ( $\chi^2=29.53$ , p<0.001)	Correlational only, cannot say info sheet caused improvement. Having more effective analgesic drugs administered and better analgesic drug control.	Uneven gender distribution between groups.

Unsworth et al. 2007 UK RCT	Parents of children (n=88). Surgery: ENT	To determine whether the use of a self-report pain scale would result in children receiving more analgesic drugs.	Provision of pain assessment tool Wong-Baker scale to determine child pain intensity Comparison: standard care	No	No	Improved administration of codeine as instructed (24% codeine administration [control group], 37% [intervention group]; p=0.004) and reduced inappropriate administration of analgesic drugs (69% control group v 39% in intervention group; p=0.001).	Intervention is ineffective. This may have been due to small sample size.	Insufficient sample size.
Franck et al. 2007 UK RCT	Parents of children (n=25). Surgery: various	To determine whether parental pain assessment documentation and analgesic drug administration increased with the use of a temporary tattoo of a pain intensity scale.	Provision of pain assessment tool Temporary tattoo Children given temporary tattoo of pain assessment scale Comparison: fun tattoo and paper pain scale.	No	No	More pain assessments at day 1 (3.0±1.16 vs. 1.93±.88; P<0.05).	Intervention may be helpful but alone is insufficient. Conclusions limited by lack of power.	Pilot study, underpowered and not designed to take into account the unanticipated effect of PCA / EA and or PCS. Heterogeneous samples from different wards where different practices used. Block randomization is not true randomization.

Kankkunen et al. 2009 Finland RCT	Parents (n=50). Surgery: unspecified	To evaluate the influence of parental use of Parents' Post-Operative Pain Measure on the use of pain medication at home.	Provision of pain assessment tool. Parents Post-Operative Pain Management tool provided to parents. Comparison: standard care.	No	No	No differences in problems faced by parents	Parents who had pain assessment tool may have been more aware of pain but did not act on it. This intervention alone is insufficient.	Alternated allocation isn't randomization. Potentially underpowered and small sample size led to non-significant findings. No demographic details provided of participants who withdrew.
Sutters et al. 2012 US Mixed methods	Parents of children (n=47). Surgery: ENT	To evaluate the feasibility of scheduled analgesic drug dosing following outpatient tonsillectomy to optimize pain management.	Multifaceted intervention Education on assessment, ATC instruction, provision of timer, written information, follow up phone calls, nurse coaching. Comparison: no control	Yes but no control	Yes but no control	Side effects, sleep and oral intake measured but no control group	Effectiveness of intervention attributed to the combination of the specific analgesic drug chosen (acetaminophen with hydrocodone) and ATC dosing. Daytime sedation, nausea and constipation were reported as intervention side-effects. Sedative effects of analgesic drug rather than pain reduction may have led to lower pain scores. Pain intensity only measured twice and fluctuations in intensity not detected. Results may be due to surgical technique.	No control group prevents any meaningful conclusions of intervention efficacy.

Walther-Larsen et al. 2016 Denmark Prospective observational cohort	Parents of children (n=149). Surgery: various	To determine postoperative pain intensity after a structured intervention for pain management.	Multifaceted intervention Pain assessment tool, tailored provision of analgesic drugs, and parental education written and verbal. Comparison: no control	Yes but no control	No	n/a	The intervention was successful but the authors are not able to hone in on a specific aspect leading to the success.	No control group prevents any meaningful conclusions of intervention efficacy.
Sepponen et al. 1999 Finland Pre and post experimental	Parents (n=227). Surgery: ENT	To describe how parents manage their child's postoperative pain at home following day-case surgery.	Doctor and nurse education Staff training program to improve analgesic drug medication practices, 1 hr lecture, 2 weeks bedside teaching. Comparison: pre-intervention parents	No	Yes, analgesic drug administration increased from 68% pre intervention to 80% post intervention (p=0.028).	Ibuprofen use increased from 28% pre intervention to 52% post intervention (p=0.002), acetaminophen sig decreased from 56% pre intervention to 24% post intervention (p<0.001).	The training hospital staff improved written and verbal information supplied to parents. Use of suppositories is discussed.	Inferential statistics are not described. Methodology may have caused the study to be confounded by recall and social desirability bias.

Palermo et al. 2009 US RCT	Children (n=48) and their parents. Chronic pain	To evaluate a more accessible treatment approach for chronic pediatric pain using an Internet-delivered family CBT intervention.	Family CBT via internet Web-based Management of Adolescent Pain: 2 websites (child and parent). 3 sections: homepage, treatment modules, daily diary. Comparison: wait list control.	Yes (mean difference 1.17, p=0.03)	n/a not assessed	Activity limitations (mean difference 2.74, p=0.004). No significant difference on depressive symptoms, parental response, treatment acceptability, satisfaction.	Therapy was successful due to relatively high dose of parental involvement and provision of parent strategies (as opposed to primarily child involvement).	Block randomization is not true randomization although blocks were allocated using random number generator.
Hegarty et al. 2013 Australia RCT	Children (n=181) and their parents. Surgery: various	To investigate whether issuing parents with take-home analgesic drugs would improve postoperative pain scores and/or parental satisfaction.	Hospital supplied analgesic drugs Parents supplied with take home hospital supplied analgesic drugs. Comparison: parent supplied analgesic drugs.	No	No	No differences in nausea, vomiting or sleep	Parents already have medications at home so providing them does not make a difference to effective pain management. Others barriers to effective pain management exist and should be investigated.	Block randomization is not true randomization. Homogeneity of groups not assessed and demographics not provided. Reasons for withdrawals not provided.



Paquette et al. 2013 Canada RCT	Parents of children (n=45). Surgery: ENT	To determine if a nurse telephone follow-up with parents could decrease pain intensity, incidence of postoperative complications, and additional healthcare resource use.	Nurse telephone follow up Phone call on days 1,3,5 and 10 to provide support and information. Comparison: standard care	No	Yes at day 1 ( $\chi^2(1) = 6.429$ , $P=0.01$ ) and day 3 ( $\chi^2(1) = 9.911$ , $P=0.002$ )	Increased constipation at day 3 ( $\chi^2(1) = 13.672$ , $P<0.001$ ) and fluid intake at day 1 ( $\chi^2(1) = 7.202$ , $P=0.007$ ) and 3 ( $\chi^2(1) = 5.909$ , $P=0.015$ ). No significant difference in vomiting, fever, dizziness.	The intervention was ineffective. Potentially due to insufficient analgesic drug power, insufficient sample size, or difference in samples pre-intervention.	Underpowered. Significant group difference in vomiting pre-intervention so groups may not have been equal to start.
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Table 3: Reasons authors attributed to the success or failure of interventions

Category	Subcategory	No. of references	Exemplars
Characteristics of the intervention	Complex intervention	7	"Instead of addressing only one of many barriers to effective pain management following day surgery in children, we decided to implement as many interventions as feasible." (Walther-Larson et al., 2015)
	Tailored	3	"A limitation of this study is that the ... booklet used in this study was a general booklet ... booklet more specific to day surgeries, with step-by-step instructions for postoperative pain management, may be even more effective..." (Chambers et al., 1997)
Components of parental pain management	Analgesic effectiveness	8	"Development of more optimal analgesic agents is needed to lower pain intensity." (Paquette et al., 2013)
	Pain education	7	"...the need for additional education for home pain and symptom management that provides knowledge about interventions that can be implemented from the time of discharge through the lengthy recovery." (Wiggins et al., 2009)
	Pain assessment tools	2	"In future studies of pain assessment ... could turn out to be a valuable tool, both in research and clinical care." (Walther-Larson et al., 2016)
	Attitudes	2	"This study also provides some preliminary evidence indicating that both parents' attitudes toward children's pain medications and how they assess their children's pain contribute independently to how they medicate their children's pain." (Chambers et al., 1997)
Key features of the research	Adequate sample size	7	"... it was underpowered, which could result in a failure to observe a difference when in truth there was one." (Franck et al., 2007).
	Measure of adherence	2	"... one limitation of this investigation is the absence of a direct measure of parental compliance with implementation of the guidelines."(Allen & Shriver, 1998)
	Measure of pain behavior	1	"Pain behaviour or overall pain may capture the effects of the intervention better than pain intensity." (Helgadottir & Wilson, 2014)
	Measure of sedation	1	"The sedative properties of acetaminophen and hydrocodone may have affected the interpretation of behavioural observations and contributed to lower FLACC scores." (Sutters et al., 2012).

## Figures

Figure 1: Search results and study selection

