


# Cancer-Related Pain and Pain Management: Sources, Prevalence, and the Experiences of Children and Parents

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## Abstract

Advances in treatment mean children are increasingly cared for by their parents at home, leading to a shift in responsibility from health care professionals to parents. Little is known about parents' pain management experiences and the etiology of pain experienced by children with cancer especially when at home. A rapid review of the literature was undertaken investigating children's cancer-related pain, with emphasis on the management of pain outside the health care setting. Electronic databases were searched and a quality assessment was conducted. Forty-two articles were included. Despite advances in pain management techniques, children with cancer regularly cite pain as the most prevalent symptom throughout the cancer trajectory. The source of pain is usually treatment side effects or painful procedures. Parents find dealing with their child's pain distressing and demanding and may hold misconceptions about pain management. Findings indicate a need for more robust research into parental pain management leading to the development of effective pain management resources for parents.

## Keywords

cancer, pain, pain management, children, parents, rapid structured review

## Introduction

In the United Kingdom, 1500 children, aged 0 to 14 years, are diagnosed with cancer every year (Cancer Research UK, 2010). Leukemia, central nervous system tumors, and lymphomas collectively account for 66% of the cancers diagnosed. Incidence rates are highest in children younger than 5 years, although this varies by tumor type, and is higher in boys than in girls across all ages (ratio of 1.2:1.0). The GLOBOCAN project provides an estimate from 2008 of incidence and mortality (<http://globocan.iarc.fr/Default.aspx>); it is estimated that annually there were 175 000 new cancer cases in children aged 0 to 14 years and that 96 000 children died from cancer (Calaminus, Birch, Hollis, Pau, & Kruger, 2013). Although incidence rates of childhood cancer have increased gradually in recent decades, mortality rates have declined significantly; 78% of children in the United Kingdom can now expect to survive for 5 years or more compared with fewer than 28% in the late 1960s (Cancer Research UK, 2010).

Pain has been reported as a significant problem for children with cancer. Parents have listed pain as the most problematic area for their child when receiving cancer treatment (Hedström, Haglund, Skolin, & von Essen, 2003; Poder, Ljungman, & von Essen, 2010). Similarly, children have described pain as the most frightening and anxiety-provoking part of being in hospital (Jacob, McCarthy, Sambuco, & Hockenberry, 2008). Children with cancer regularly experience pain as a result of the disease, side effects of treatment, procedures associated with medical management, and from generalized psychological distress (Department of Health, 2011; Fortier,

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Sender, & Kain, 2011; World Health Organization, 2012). Pain caused by the disease process arises from tumor involvement with bone, soft tissue, viscera, and central or peripheral nervous system (Oakes, 2011). The painful effects of chemotherapy treatment include mucositis, mucosal damage, gastritis, infection, and peripheral neuropathy (Van Cleve et al., 2004). Pain resulting from treatment with radiation includes myelopathy, plexopathy, dermatitis, and burns (Fortier et al., 2011; World Health Organization, 2012). Children with cancer commonly undergo frequent painful procedures such as surgery, lumbar punctures, bone marrow aspirations, biopsy, and venepunctures during the course of treatment (Cline et al., 2006; Walco, Conte, Labay, Engel, & Zeltzer, 2005). As unrelieved pain has negative psychological and physiological consequences in both the short and long term (Pate, Blount, Cohen, & Smith, 1996; Taddio & Katz, 2005), and in cancer has been linked to changes in quality of life, depression, and posttraumatic stress (Ruccione, Lu, & Meeske, 2013), it is important to ensure that pain is managed effectively. One painful procedure poorly managed can mean that unnecessary levels of anxiety are associated with subsequent procedures, which can lead to posttraumatic stress disorders (Stuber, Christakis, Houskamp, & Kazak, 1996). With children facing repeated painful procedures health care professionals (HCPs) have a responsibility to ensure that these procedures are managed well and that pain and distress are minimized as far as possible. This is particularly pertinent as most cancer-related pain can be managed and is therefore not an unavoidable consequence of treatment or disease.

It is worth noting that pain management differs in the palliative phase of the disease, as during the end-of-life stages treatment is focused primarily on improving the quality of life and is often associated with less aggressive treatments (Roza, Horton, Johnson, & Anderson, 2014). Conversely, treatment plans preceding the palliative phase are primarily curative often at the cost of quality of life. In addition, the palliative phase is often accompanied by complications, such as difficulties with oral intake which prevent the administration of pain management drugs orally (Marks, Keefer, & Saul, 2013). These alter the nature of pain management during this phase. For this reason, this review has focused on the nonpalliative phase of the disease trajectory.

Changing patterns in health care delivery and therapeutic approaches mean children with cancer spend less time in hospital and are increasingly cared for by their parents at home, attending hospitals on an outpatient basis and being admitted only where necessary (Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011). This entails a shift in responsibility for pain management from clinicians to parents. Nurses need to be aware of this shift

in care and its implications for their practice in terms of minimizing children's pain while in hospital as well as educating parents in the management of their child's pain while at home. Children with cancer when cared for at home are likely to be dependent on their parents to both assess and treat their pain, and yet relatively little is known about pain assessment and parental decisions around pain management in this population (Fortier et al., 2011). A critical appraisal of studies that have examined the pain experience of children with cancer is therefore timely, and will indicate future research pathways.

## Methodology

A rapid structured review of the literature was undertaken. Our aims were to

1. Explore the sources and prevalence of pain in children with cancer
2. Describe the impact of pain on the child and other family members
3. Explore parents' attitudes to pain and pain medications
4. Describe parents' experiences of managing children's cancer-related pain at home

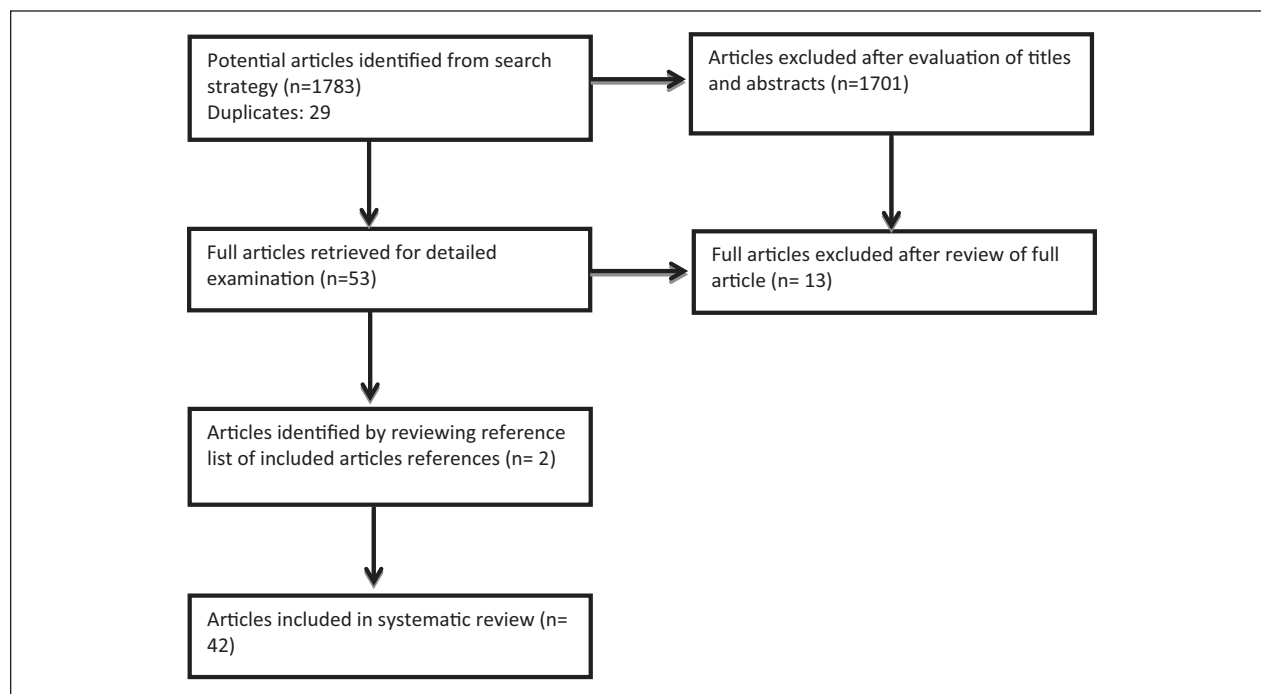
Rapid structured reviews are used to summarize and synthesize research findings within a given timeframe (Armitage & Keeble-Ramsay, 2009; Ganann, Ciliska, & Thomas, 2010). They differ from a systematic review in relation to the extensiveness of the literature search and the methods used to undertake the analysis (Armitage & Keeble-Ramsay, 2009; Smith, Cheater, & Bekker, 2013). Rapid structured reviews are considered to be appropriate and a useful approach to identify research priorities, or in this case, to contextualize empirical studies prior to undertaking research into how parents manage their child's cancer-related pain at home.

## Data Sources and Selection

Electronic database searches (PsychInfo, CINAHL, PubMed, and EMBASE) were conducted by one of the authors (RP) using the following search terms: child OR children OR pediatric OR paediatric, AND cancer pain. To ensure relevant articles were not missed in the database, the reference list of each included article was hand-searched. One of the authors (RP) carried out initial screening of all the databases using study titles and abstracts and recorded the number meeting the criteria, the number excluded, reasons for exclusion, and if the article had to be reviewed to determine eligibility. Any articles where there was uncertainty were reviewed by another author (AT). The number of articles extracted

**Table 1.** Database Search Results.

Database	No. of Articles Retrieved From Literature Search	No. of Full Articles Retrieved
Psychinfo	71	4
CINAHL	345 (8 duplicates of included articles from other databases)	25
Pubmed	873 (3 duplicates of included articles from other databases)	10
EMBASE	492 (17 duplicates of included articles from other databases)	26

**Figure 1.** Flow diagram for retrieved, excluded, and included studies.

from each database can be seen in Table 1. Forty-two articles were included in the review. The selection process is illustrated in Figure 1.

Inclusion criteria were the following:

1. Peer-reviewed research exploring pain in children with cancer
2. Primary research of any methodology
3. Published in English between 1990 and October 2013

Exclusion criteria were the following:

1. Studies relating primarily to the palliative phase of the disease
2. Studies relating to the effectiveness of analgesic medications
3. Studies relating to organizational structure of pain management services
4. Studies that only investigated HCPs perspectives

5. Expert opinion, reviews, books, book chapters, commentaries, and dissertations

### Assessment of Methodological Quality

Regardless of research design articles were included if they met the inclusion and exclusion criteria. The only exception to this was one article which provided no details about the research methodology, and was excluded after a review of the full article (Geeta et al., 2010). A framework developed by Caldwell, Henshaw, and Taylor (2011) guided the assessment of scientific rigor of the articles. This framework consists of an overall approach to study critique using specific items based on the methodology. This includes a set of general items which can be applied to both qualitative and quantitative articles and a second set of items which is divided between qualitative and quantitative articles. Examples of items include the extensiveness of the literature review, considerations of the appropriateness of the design in light of the aims and an

assessment of generalizability/transferability. It does not produce a single numerical score to represent rigor but rather guides the reader to examine all aspects of a study to help determine strengths and weaknesses. Articles were assigned to each of the four authors, who worked independently using the framework to assess quality.

### *Data Extraction and Synthesis*

Data from each study was extracted by one author (RP) using an investigator-customized form specifying authors, country, study design, sample characteristics, data collection techniques, and findings linked to children's cancer-related pain.

### **Results**

Of the 1783 publications initially identified, 29 were duplicate articles, 1701 were excluded after checking the titles and abstracts, a further 13 publications were excluded after a full review leaving 40 publications. A further two publications were included after systematically searching the reference lists of included publications. Of the 42 studies meeting the inclusion criteria, 10 included data sources of pain in children with cancer, 27 included data on prevalence of pain in children with cancer, 4 included data on children's cancer-related pain management, 7 included data on parental attitudes to pain, and 6 included data on impact of pain on the family. There was a range of quantitative, qualitative, and mixed-methods studies, using multiple data collection techniques. The results of the quality assessment and the categorization of articles are summarized in Table 2.

Overall very few studies had findings that could be generalized. Many had small sample sizes that limited the power of statistical analysis. Others used questionnaires for data collection that had not previously been validated. Many lacked details of population and sample demographics that meant the authors were unable to ascertain the representativeness of the sample. There was a range of methodologies represented with most studies either using questionnaires or interviews. Few studies included children's voices and many authors chose to use parents' views as proxy for children's voices. There were no randomized controlled trials.

Findings have been organized into five main categories: sources of pain, prevalence of pain, pain management, parental attitudes, and impact of pain on the family. Most studies contained data relating to more than one category.

### *Sources of Pain in Children With Cancer*

Although in early studies children with cancer report more pain from the disease itself (P. A. McGrath, 1990), with the development of more aggressive therapies, there is a

trend toward studies reporting more pain from treatment and procedures than from the cancer (Blount, Piira, Cohen, & Cheng, 2006; Elliott et al., 1991). Several studies report that treatment- and procedure-related pain are more problematic than pain from the disease itself (Fowler-Kerry, 1990; Hedström et al., 2003; Ljungman, Gordh, Sörensen, & Kreuger, 1999; Ljungman, Kreuger, Gordh, & Sörensen, 2006; P. J. McGrath et al., 1990). Although preventive pain-relief measures are available for such procedures, a large number of children continue to report ongoing procedure-related pain throughout treatment (Ljungman et al., 1999; Ljungman, Gordh, Sörensen, & Kreuger, 2000; Spagrud et al., 2008; Walco et al., 2005).

There was limited evidence on how well procedural pain is managed. In a qualitative study, eight adolescents with cancer reported having their own coping strategies for managing procedures such as trying to distract themselves by thinking of something else, singing, or counting (Fowler-Kerry, 1990). Some adolescents articulated a preference for named HCPs whose presence could alleviate their distress during painful procedures. However, this study reported such strategies as being ineffectual.

Spagrud et al. (2008) found adult "coping-promoting" behaviors such as trying to distract their child enabled the child to cope with the procedure better and demonstrated lower levels of distress. Conversely, adult behaviors such as showing empathy and reassuring their child were classed as adult "distress-promoting" behaviors and led to higher levels of distress in children. An additional finding was that peripheral needle access caused no higher distress than port access. However, for ethical reasons the groupings could not be controlled for, and use of topical analgesics could not be standardized, both these variables may have affected the findings.

There is some evidence that traditional measures of recording procedural pain through observation may underestimate levels of pain in children with cancer (Walco et al., 2005). Walco and colleagues made behavioral observations before, during, and after procedures and correlated them with physiological parameters such as heart rate and salivary cortisol. They found that while observational and physiological parameters correlated highly, physiological parameters often indicated higher levels of distress than indicated by observational instruments. Furthermore, cognitive-behavioral techniques and topical analgesia appeared to have a greater effect at reducing behavioral distress than either light or deep sedation. No studies to date have evaluated the effectiveness of interventions in children's cancer pain caused by procedures.

### *Prevalence of Pain in Children With Cancer*

Several studies have explored the amount of cancer-related pain experienced by children. As stated above, data have more often been collected from parents or

**Table 2.** Summary of Studies Included in the Review.

Study	Theme	Aims	Strengths	Weaknesses
Fowler-Kerry (1990) USA, Ethnoscience study	Source	To discover and classify perceptions of past painful procedures in survivors of cancer	Strengths: Results were given intra- and intersubject agreement by participants. Good description of methodology, rationale and key concepts Strengths: The first study to provide data of this kind Strengths: Descriptive and inferential statistics were appropriately presented	Weaknesses: Very little information on data analysis. Small sample but appropriate for preliminary study Weaknesses: Sample size was small and from one hospital so cannot be generalized Weaknesses: Conclusion was inconsistent with the findings. The authors concluded that prevalence of pain in this population is low. However, in the discussion they stated that high numbers of outpatients sampled may have led to low pain levels reported Weaknesses: No information on analgesia administered. Few details on recruitment process on the population and sample. Only views of parents' presented
P. J. McGrath et al. (1990) USA, Questionnaire	Source	To determine the source and extent of pediatric cancer pain	Strengths: Comprehensive literature review, description of methodology, aims, and presentation of results. Results could be transferred to clinical populations easily	Weaknesses: Difficult to judge whether inferential statistics were appropriate since results for this was not reported. No power calculation provided. Qualitative findings from a study published elsewhere were brought into the results section confusing the study findings
Elliott et al. (1991) USA, Questionnaire	Source	To gather epidemiologic data to help develop future pain management studies and to study the feasibility of performing formal pain intensity assessment in a group setting	Strengths: Both measures have previously established reliability and validity. Appropriate descriptive and correlational statistics used	Weaknesses: Much of the detail of this study has been excluded due to being published elsewhere. Discussion is limited. No mention of limitations of the study, future research directions or relation to previous research
Ferrell, Rhiner, Shapiro, and Dierkes (1994) USA, Interviews	Attitudes and Impact	To describe family factors and measure knowledge and attitudes in effective pain management	Strengths: Qualitative nature of study is clear. Results well presented	Weaknesses: Limited detail on data collection. Data collection tools have not been previously used in this context
Ferrell, Rhiner, Shapiro, and Strause (1994) USA, Questionnaire	Impact	To describe the quantitative effect of pain in children with cancer on the family	Strengths: Population, sample and recruitment method well defined and described	Weaknesses: Lack of reported power calculations means it is difficult to assess whether sample size is sufficient
Rhiner, Ferrell, Shapiro, and Dierkes (1994) USA, Interviews	Pain Management and Attitudes	To study the role and experience of parents when managing pediatric cancer pain	Strengths: Some attempt to measure analgesia given in pain diaries. Longitudinal data added greater depth but only a sample of 2. Data collection methods valid and reliable	Weaknesses: Methodology was not well justified. Longitudinal aspect had small sample size. Data collection was via questionnaire but reported as interview. Interview aspect of data collection not well used
Bossert, Van Cleve, and Savedra (1996) USA, Interviews	Prevalence and Pain Management	To explore pain in children with cancer away from the health care setting	Strengths: Population and sample well described so representativeness can be assessed. Validation and reliability analysis provided for target population	Weaknesses: Sample size was small although collected from two countries. Focus of the article was on the development of the tool so generalizability of findings is limited
Ljungman, Gordh, Sörensen, and Kreuger (1999) Sweden, Interviews	Source	To evaluate extent and causes of pain, pain assessment, management and adverse effects of pain management	Strengths: Appropriate steps taken to ensure reliability and validity of data collection tools (this was the aim of study)	Weaknesses: Nurses and nursing assistants grouped as one in analysis. Nurses may struggle to recall distressing events for a particular patient. Retrospective data collection may be subject to memory distortions. No discussion of different methodology for younger children
Collins et al. (2000) USA, Questionnaire/Review of patient records	Prevalence	To determine symptom prevalence, characteristics, and distress in children with cancer	Strengths: Included perspective of nurses, parents, and children. Good age range of children. Results generalizable as sample bias addressed	
Ljungman, Gordh, Sörensen, and Kreuger (2000) Sweden, Questionnaire/Interview	Source	To investigate how cancer pain experience changes with time		
Collins et al. (2002) Australia and UK, Questionnaire	Prevalence	To evaluate the reliability and validity of a revised Memorial Symptom Assessment Scale in patients aged 7 to 12 years		
Hedström, Haglund, Skolin, and von Essen (2003), Sweden, Interviews/Questionnaires	Source and Prevalence	To find out what aspects of the disease/treatment are most distressing		

(continued)

Table 2. (continued)

Study	Theme	Aims	Strengths	Weaknesses
Van Cleve et al. (2004) USA, Interview/Questionnaire	Prevalence and Pain Management	To describe children's pain experience, strategies for management, and their effectiveness during first year after diagnosis	Strengths: Limitations were addressed in the discussion. Good consideration of ethical issues	Weaknesses: Limited to leukemia only but findings were similar to studies including all types of cancer. Parental report for younger children and self-report for older children may have accounted for the differences in findings
Varni, Burwinkle, and Katz (2004) USA Questionnaire	Prevalence	To investigate cross-sectional and longitudinal associations between pain and emotional distress using Paediatric Quality of Life Inventory	Strengths: Good methodology for including children, adolescents, and parents in one study. Well described and justified	Weaknesses: Dividing the sample into age groups limited the statistical power of some tests and the generalizability of findings. Did not differentiate for treatment, procedural or disease-related pain
Forgher, Finley, and Armaout (2005) Jordan, Chart audit/ Interviews	Prevalence and Attitudes and Impact	To audit pain prevalence, and to assess parents' attitudes toward cancer pain and its treatment	Strengths: Population and sample were well described. Methodology was identified and justified	Weaknesses: In addition to small sample sizes, the study was conducted in a developing country where parents may hold different cultural beliefs. Therefore, applicability to United Kingdom is limited. (However, similarity of findings to other literature is of interest.) Limited data analysis information provided for either study
Hedström, Ljungman, and von Essen (2005) Sweden, Interviews	Source	To study perceived distress among adolescents recently diagnosed with cancer	Strengths: Authors have taken steps to minimize sample bias. Limitations were discussed in the discussion	Weaknesses: Large number of statistical analyses increases risk of Type I errors. Data collection was via questionnaire but reported as interview
Walco, Conte, Labay, Engel, and Zeltzer (2005) USA, Observation/Self-report	Source	To examine the relationship among different indicators of pain and distress, including self-report, behavioral observations and physiological parameters, in children with cancer undergoing invasive procedures	Strengths: Population and sample demographics were well described. Data collection tools have been previously used in published material	Weaknesses: No information on recruitment procedure. Patients were not randomly assigned to groups limiting the validity of the study but this could not be done for ethical reasons
Ameringer, Serlin, Hughes, Friedrich, and Ward, (2006) USA, Interview and Questionnaire	Prevalence	To explore concerns that adolescents with cancer have regarding pain and to use this to develop the Adolescent Barriers Questionnaire	Strengths: Data collection methods well described and appropriate. Standardization to reduce bias. Data analysis methods have been previously validated	Weaknesses: Very few participants in both studies and no obvious barriers to further recruitment. Not a problem for the purpose of the study (questionnaire development) but limited generalizability of findings
Badr Zahr, Puzantian, Abboud, Abdallah, and Shahine, (2006) Lebanon, Observation	Attitudes	To examine the relationship between different indicators of pain and distress in Lebanese children with cancer undergoing catheter insertion	Strengths: Rationale for choice of study design described and major concepts explained. Using a range of data collection tools enabled validation of the new tool	Weaknesses: Not all results reported had significance levels. Small sample size from Lebanese population limits generalizability
Calissendorff-Selder and Ljungman (2006) Sweden, Interviews/Questionnaire	Prevalence	To study variations in pain and quality of life in adolescents with cancer during treatment	Strengths: Data collection tools have been previously used but no reliability or validity scores were referenced in this study	Weaknesses: Large variation between participants in time since diagnosis. No power calculations described despite having stated in the discussion that the study may be underpowered. Small samples mean generalizability is limited
Gedaly-Duff, Lee, Nail, Nicholson, and Johnson (2006) USA, Diaries/Wrist actigraphy/Questionnaires	Prevalence	To look at the feasibility of collecting data from home	Strengths: Clear aims and methodology. Appropriate presentation of results	Weaknesses: No description of data analysis. No control for period of treatment. Small sample, pilot study, so no generalizability
Ljungman, Kreuger, Gordh, and Sörensen (2006) Sweden, Questionnaire/Interview	Source and Prevalence and Attitudes	To compare viewpoints of children and parents with professionals on pain in cancer	Strengths: Good description of population and sample. High uptake and low dropout rate	Weaknesses: Reliability and validity of data collection tools cannot be assessed due to very little information on tools used. Differences between groups may be attributed to differences in data collection between groups. Children and parents may be subject to interviewer bias compared with health care professionals who completed anonymous questionnaires

(continued)

**Table 2. (continued)**

Study	Theme	Aims	Strengths	Weaknesses
Williams, Schmideskamp, Ridder, and Williams (2006) USA, Questionnaire	Prevalence	To assess symptoms, describe responses to alleviate symptoms, and examine relationship between symptoms and functional status	Strengths: Measures clearly identified and justified. Suitable methodology, and reporting of findings for a pilot study	Weaknesses: Small convenience sample suitable for pilot study but limiting strength of findings. Article relates entirely to parent reported symptoms in child and uses a measure developed for children but only on their adult parents. No detail on patients who declined to participate
Enskär and von Essen (2007) Sweden, Questionnaire	Prevalence	To describe the prevalence of physical and psychosocial distress, coping, support, and care among adolescents and young adults both undergoing and off cancer treatment	Strengths: Data collection tools are valid and reliable	Weaknesses: No information regarding consent of participants. Article related to distress and coping in adolescents; limited relation to pain. Inter- and intragroup variation may be too large and therefore limit generalizability but this is acknowledged by authors
Friedrichsdorf, Finney, Bergin, Stevens, and Collins (2007) Australia, Interview	Prevalence	To determine the prevalence, characteristics, and impact of breakthrough pain in children with cancer	Strengths: Clear aims, population, and sample well described, results presented appropriately and discussion comprehensive	Weaknesses: Questionnaire adapted for this study only tested for face validity. Small sample size limited generalizability and may have accounted for the lack of statistically significance between breakthrough pain and depression or anxiety
Jacob, Hesselgrave, Sambuco, and Hockenberry (2007) USA, Questionnaire	Prevalence	1. Characterize intensity, location, and quality of pain 2. Evaluate pain management 3. Examine relationships between pain and perceptions of sleep and activity	Strengths: Inclusion criteria described. Data collection tools had been previously validated	Weaknesses: Lack of demographic data of population and the small sample size limited generalizability. Pain data not collected at home so on discharge unknown whether pain fluctuated in these patients or not
Jacob, McCarthy, Sambuco, and Hockenberry (2008) USA, Interview	Prevalence	To describe pain, to examine factors relating to pain, and to identify medications received for pain in Spanish-speaking children with cancer	Strengths: Data collection tools well described, valid, and reliable	Weaknesses: Population not described and so cannot say whether sample is representative. Only a small sample of 8 children reported severe pain so tests lacked power and generalizability
Yeh et al. (2008) Taiwan, Questionnaire	Prevalence	To derive symptom clusters occurring in older pediatric patients with cancer	Strengths: Data collection tool appropriate and validated for use in children, appropriate measures taken for translation and validated in target population. Well-described population	Weaknesses: Due to cultural descriptions of sickness this study may not be generalizable to the United Kingdom
Spagrud et al. (2008) Canada, Experimental	Source	To compare pain and distress between peripheral, port, and external lines. To examine the impact of adult behavior on children's coping	Strengths: Group allocation was done ethically. Previously tested and validated (although not in this context) observation tools used by researchers	Weaknesses: Recruitment procedure was unclear. No impact of topical anesthetic may be due to the fact that it was not systematically monitored
Hechler et al. (2009) Germany, Interview	Prevalence	To determine if there are sex differences in current perception, past recollection, and pain ratings in adolescents with cancer	Strengths: Sampling methodology, data collection tools, and data analysis well described and justified	Weaknesses: Low uptake of recruitment may have led to a biased sample and therefore low generalizability
Post-White et al. (2009) USA, Questionnaire	Impact	To look at complementary and alternative medicine in specialty areas of pediatrics	Strengths: Validity of data collection tools described. Comprehensive literature review, rationale for study design given and sample well described	Weaknesses: Sample size limited generalizability Not specifically addressing cancer.
Yeh et al. (2008) Taiwan, Questionnaire	Prevalence	To assess and describe the prevalence of symptoms in Taiwanese pediatric cancer patients	Strengths: Data collection tools well described, previously validated, translated for study using standardized procedure	Weaknesses: Population not clearly defined. Study conducted with Taiwanese patients and so generalizability to the United Kingdom may be limited
Pöder, Ljungman, and von Essen (2010) Sweden, Questionnaire	Prevalence and Impact	To describe most problematic symptoms from parents' perspective and how they relate to stress	Strengths: Data collection tools had been previously validated; however, this was in a different context. Because of large sample findings could be generalized; however, not to all cancer populations as these populations were not equally represented across time points	Weaknesses: The study did not consider the child's self-report of symptoms; however, findings concur with studies of child self-report. Methodologically, the completion of the Memorial Symptom Assessment Scale may itself have caused the parents stress as the process of completion heightens their awareness of their child's symptoms. Therefore, the order in which the questionnaires were completed may have affected results

(continued)

Table 2. (continued)

Study	Theme	Aims	Strengths	Weaknesses
Walker, Gedaly-Duff, Miaskowski, and Nail (2010) USA, Questionnaire	Prevalence	To describe differences in occurrence, frequency, intensity, and distress of symptoms prior to and 1 week following chemotherapy	Strengths: Data collection methods previously validated. Appropriate statistical analysis	Large sample and longitudinal design adds to validity Weaknesses: Cannot be clear whether sample is reflective of population. Heterogeneous sample may have limited generalizability
Flury, Caffisch, Ullmann-Bremi, and Spichtig (2011) Switzerland, Interviews	Impact	To explore experiences of parents after diagnosis and initial discharge	Strengths: Methodology justified and main concepts described. Results presented to participants to validate	Weaknesses: No sampling methodology provided. Very small sample therefore cannot be generalized
Lu et al. (2011) Taiwan, Interviews	Prevalence and Pain Management and Attitudes	To understand the main caregivers' lived experiences in managing pain for children with neuroblastoma	Strengths: Population described and sample representative. Sufficient detail describing data collection method	Weaknesses: Sample included neuroblastoma patients only so cannot be generalized to other cancer populations. Authors acknowledge interviews conducted in one hospital in Taiwan so differences in nationality, lifestyles, values, and religion may limit generalizability. Interviewer regularly visited patient prior to interview to build relationship but may have had the confounding effect of introducing bias
Miller, Jacob, and Hockenberry (2011) USA, Questionnaire	Prevalence	To describe prevalence, frequency, severity and distress of hospitalized children with cancer	Strengths: 100% response rate, sample reflected population. Data collection tools previously validated. Results generalizable	
Baggett, Cooper, Marina, Mathay, and Miaskowski (2012) USA, Questionnaire	Prevalence	To identify numbers and types of symptom clusters in children with cancer	Strengths: All data collection tools had previously established validity and reliability. Large sample size gives power to data analysis statistics which are well described and justified	Weaknesses: The KPS scale had not been used in published pediatric oncology research. The retrospective nature of recall meant questionnaire responses were subject to memory. The study did not consider longitudinal changes in clusters. While convenience sample described and demographic details provided, total population not described so uncertain that sample is reflective of population
Fortier et al. (2012) USA, Questionnaire	Attitudes	To examine parents' attitudes toward pain medication and expression in children with cancer	Strengths: Validity and reliability of instruments used had been previously supported and were appropriate for the aims	Weaknesses: Limited by a convenience sample which was not stratified for those on active treatment or not
Van Cleve et al. (2012) USA, Questionnaire	Prevalence	1. Examine child and nurse reported symptoms 2. Compare Latino and Caucasian reports of symptoms by age, gender, and diagnosis 3. Examine change in symptoms over time	Strengths: Inclusion/exclusion criteria, recruitment strategy and reasons for dropout explained. Data collection tools had been previously validated	Weaknesses: As children who were too sick or in too much distress were not included, this may have skewed results
Hedén, Pöder, von Essen, and Ljungman (2013) Sweden, Interviews	Prevalence	To describe parents' perception of child's symptoms throughout the cancer disease trajectory	Strengths: Data collection tools had been tested for validity and reliability. Population and sample well described	Weaknesses: Small sample from one Swedish hospital therefore cannot be generalized. Only parental perceptions of pain measured, no actual pain levels for children were gathered. Parent/child relationship should be considered when parental report is used
Rucciono, Lu, and Meeske (2013) USA, Interviews	Prevalence	To assess adolescents' self-report health-related quality of life soon after completion of treatment	Strengths: Based on well-described measures and theoretical underpinning. Population and sample clearly described. Data collection tools had been tested for validity and reliability	Weaknesses: Authors acknowledged a bias in the sample that limits the generalizability of the study



HCPs rather than children themselves (Hedén, Pöder, von Essen, & Ljungman, 2013; Ljungman et al., 2006; Miller, Jacob, & Hockenberry, 2011; Pöder et al., 2010; Wolfe et al., 2000). It is difficult to obtain a single figure for the prevalence of pain in children with cancer as studies have looked at different populations, timeframes, and aspects of pain. Pain is regularly one of, if not the most commonly reported symptom (Collins et al., 2000; Hedström et al., 2003; Miller et al., 2011; Williams, Schmideskamp, Ridder, & Williams, 2006). Collins et al. (2000) found that pain was one of the top seven most commonly reported symptoms and was the most common symptom for inpatients. Miller et al. (2011) found pain was one of the top five most commonly reported symptoms and was second only to nausea as the “most bothersome” symptom. More recently, it has been found that pain was the most frequent and severe symptom reported by children (Van Cleve et al., 2012). Four out of five adolescents in one study agreed that pain was an inevitable part of their cancer experience which could not be avoided (Ameringer, Serlin, Hughes, Frierdich, & Ward, 2006).

The prevalence of pain in children with leukemia has been studied longitudinally by Van Cleve et al. (2004) in a study undertaken in the United States. Pain was found to be a common symptom experienced by children in the first 12 months after diagnosis. The authors collected data on pain levels, pain frequency, pain coping, pain management strategies, and perception of management effectiveness during interviews with children ( $n = 95$ ) at seven data-collection points over a 12-month period. All the children reported current or recurrent pain at one or more data collection point.

Some studies have looked at the prevalence of pain in children depending on the stage of treatment (Bossert, Van Cleve, & Savedra, 1996; Calissendorff-Selder & Ljungman, 2006; Enskär & von Essen, 2007; Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; Walker, Gedaly-Duff, Miaskowski, & Nail, 2010). There is evidence that pain is highest at the beginning and end of the disease trajectories and that pain covaries with quality of life (Calissendorff-Selder & Ljungman, 2006). Enskär and von Essen (2007) found that 53% of adolescents on active treatment experienced pain compared with 33% of adolescents not receiving active treatment. Gedaly-Duff et al. (2006), asked children to keep pain diaries, parents to complete questionnaires and asked both to wear wrist actigraphs as measures of pain, sleep, and fatigue. They found pain accompanied sleep disturbance and fatigue throughout the 3 days following chemotherapy. Conversely, Walker et al. (2010) found pain was prevalent in 52.2% of 51 adolescents before chemotherapy but reduced to 47.8% 1 week after the administration of chemotherapy. However, the authors of this study noted that due to a small sample size, they could not account for the fact that

adolescents within the group were at different points in their disease trajectory. In addition, there is some evidence that pain is worse between 1 week and 1 month after chemotherapy (Bossert et al., 1996) so the time frame used by Walker et al. (2010) may have skewed the conclusions.

It should be noted that the majority of studies described thus far have been undertaken in Western countries (Europe and North America) and may not be globally representative or account for cultural and ethnic variation in terms of reported pain experience and prevalence. Attempts have been made to measure pain prevalence in children with cancer from non-Western cultures, which does seem to suggest a similar picture. In Jordanian children, 11% aged 2 to 17 years, had “a lot” of pain (Forgeron, Finley, & Arnaout, 2005) and in Taiwanese patients, aged 10 to 18 years, pain was prevalent in 41% and distressing in 19% of patients (Yeh et al., 2008). In a US study, it was found that 41% of children, aged 8 to 12 years, experienced pain with many Spanish-speaking children not receiving medication due to underreporting (Jacob et al., 2008).

There is limited empirical evidence that pain differs depending on gender. Hechler and colleagues found that girls self-reported higher pain intensity than boys in a sample of 122 adolescents from 28 children’s departments (Hechler et al., 2009). However, the parents of these children reported that boys had higher pain intensity than girls. As this was a retrospective study, it may be that this is a measure of gender differences in recall rather than gender differences in the experience of pain. Other studies have found no significant gender differences in pain experience among children with cancer (Jacob, Hesselgrave, Sambuco, & Hockenberry, 2007; Van Cleve et al., 2012; Walco et al., 2005).

It should be noted that some of these studies focus on adolescents’ pain, and there is some evidence that childhood cancer pain may differ depending on age (Hedström et al., 2003; Van Cleve et al., 2012; Varni, Burwinkle, & Katz, 2004). Pain from diagnostic procedures has been the most frequently mentioned distressing event for all age groups except for those aged 13 to 19 years (Hedström et al., 2003). Findings also suggest that where 57% of inpatient children experienced breakthrough pain, in the previous 24-hour period, younger children are more at risk of this (Friedrichsdorf, Finney, Bergin, Stevens, & Collins, 2007).

Younger children are underrepresented in the research with many studies focusing on school-aged children or adolescents. Van Cleve et al. (2012) found that older children had higher levels of pain than younger children but this study used only a range of 6 to 17 years. Studies which include younger children often use parental pain ratings rather than ratings from children themselves (Lu et al., 2011). This is potentially due to difficulties in obtaining pain ratings from younger children although if appropriate

pain assessment instruments are used it is possible to obtain self-reports of pain from children as young as 3 years old (von Baeyer, Chambers, Forsyth, Eisen, & Parker, 2013). Indeed, children with cancer as young as 7 years old have been shown to consistently self-report symptoms (Collins et al., 2002). It is also worth noting that the results of a systematic review indicate that parental reports of pain should only be considered an estimate of a child's pain (Zhou, Roberts, & Horgan, 2008).

Recent evidence has focused less on single symptoms, such as pain, and more on clusters of symptoms that are frequently reported together (Baggott, Cooper, Marina, Mathay, & Miaskowski 2012; Miller et al., 2011; Yeh et al., 2008). Pain is reported as a significant contributor to certain symptom clusters although there are variations between studies as to which symptom cluster pain belongs. Yeh et al. (2008) identified five symptom clusters. Pain and gastrointestinal symptoms made up one cluster but patients with pain experienced higher levels of distress in all clusters. Baggott et al. (2012) found only three clusters of which pain contributed to the neuropsychological discomforts cluster. This is a new focus of inquiry, and has much to offer. Future studies on symptom clusters should explore the relationship of pain to other symptoms, resulting in a better description of pain prevalence.

### *Pain Management Outside the Health Care Setting*

Fifteen studies included data on pain management in children with cancer outside the health care setting. The pain management strategy used most commonly by parents was the use of analgesic drugs; a strategy which decreased throughout the first year after diagnosis (Van Cleve et al., 2004). Taiwanese caregivers ( $n = 12$ , predominantly mothers), interviewed to elicit views on pain and parental pain management in children with neuroblastoma reported using pharmacological and nonpharmacological strategies to alleviate pain in their child (Lu et al., 2011). In this study, the impact of pain on the family and wider relationships emerged as the impetus for seeking mental and emotional support from family and clinicians and required families to make life adjustments. Perceptions of the disease influenced and interacted with the ways in which caregivers approached pain and its management.

Rhiner and colleagues described five themes emerging from interviews relating to family caregivers' roles in managing children's cancer pain: allow the child control, nonpharmacological interventions, restrict medications, encourage medications, and pain assessment (Rhiner, Ferrell, Shapiro, & Dierkes, 1994). Caregivers restricted the use of medications because of concerns about addiction and side effects. On the other hand, the contradictory theme of "encourage medications" related

to attempts to use analgesic drugs effectively by becoming the child's advocate and partner in the face of pain, by getting to know the medications and how best to use them, in an attempt to prevent pain. Another aspect of the study examined parents' needs in terms of assistance from HCPs. One of parents' central concerns was the need for education about pain-relief. This was especially important early in the course of their child's illness, with parents reporting that a preemptive approach could have helped alleviate their own feelings of frustration as well as their child's pain.

Bossert et al. (1996) specifically aimed to gather information from a nonhealth care setting. They found that all children experienced pain in various parts of their body lasting from seconds to hours. However, this was a small pilot study and despite aiming to gather information from outside the health care setting, data collection took place at a children's cancer clinic, the same location and on the same day as clinic appointments. Furthermore, the authors reported that children regularly gave responses talking about procedures such as lumbar punctures that could only happen within a health care setting.

### *Parents' Attitudes to Pain and Pain Medications*

Research on parental attitudes to children's cancer-related pain at home is sparse. Taiwanese parents ( $n = 12$ ) reported that they considered analgesic drugs as the most effective and direct method for managing pain (Lu et al., 2011). However, in the United States, parents ( $n = 187$ ) were found to have concerns and misconceptions about analgesic drugs and their use for children with cancer (Fortier et al., 2012). Some parents also expressed a belief that children exaggerate pain or seek attention by expressing pain. However, a significant relationship has been found between parent and child pain ratings so this belief may not affect their assessment of pain (Badr Zahr, Puzantian, Abboud, Abdallah, & Shahine, 2006).

Information about parents' perception relating to opioid analgesia has been collected in several other studies. Swedish children and parents reported that they had never refused opioids due to a fear of addiction (Ljungman et al., 2006). Taiwanese parents did not express any concerns about using opioids to manage pain in their children (Lu et al., 2011). However, Ferrell and colleagues found that parents simultaneously described restricting the use of medications because of concerns about addiction and side effects and encouraged the use of opioids to prevent pain (Ferrell, Rhiner, Shapiro, & Dierkes, 1994).

Jordanian parents ( $n = 22$ ) were interviewed as part of a study to establish pain prevalence and parental attitudes toward pain management (Forgeron et al., 2005). Parents believed that pain could and should be managed. Parents

said that they were likely to take their child to hospital when they were in pain, but it was unclear if they felt admission to hospital would be necessary if effective pain-relief could be provided at home. In relation to children's expression of pain, the majority of parents stated that children had a responsibility to express their pain, and that behavioral cues, or verbal reports were the most important ways of doing so. None of these parents expressed fear or concern over opioid use.

### *The Impact of Children's Cancer-Related Pain on the Family*

The impact of children's cancer-related pain on the family has been explored in six studies. Ferrell and colleagues interviewed 31 parents representing 21 children (Ferrell, Rhiner, Shapiro, & Dierkes, 1994). In describing children's cancer pain, caregivers reported that pain was often not taken seriously by HCPs. The diagnosis of cancer itself had a profound impact on parents, who reported feeling frustrated, helpless, and sometimes unable to adequately comfort their child. The child's pain was deeply distressing for parents, and some reported seeing their child in pain as being physically painful for themselves. Some parents also felt unprepared for managing pain at home and felt the child's pain affected all aspects of family life. Ferrell and colleagues then surveyed 39 parents representing 21 children and found that the highest area of caregiver burden was found to be the emotional response to patient symptoms including pain (Ferrell, Rhiner, Shapiro, & Strause, 1994).

Jordanian parents reported that the worst pain they experienced was the emotional pain of seeing their child in pain (Forgeron et al., 2005). In another study, out of 281 parents it was found that use of complementary and alternative medicine was higher in the cancer population when compared with other childhood conditions and that one reason regularly cited for the use of complementary and alternative medicine was that it helped parents to cope with the emotional effects of pain in their children (Post-White et al., 2009). Levels of parental stress in Swedish parents ( $n = 214$ ) was linked to symptom burden of their children ( $n = 115$ ; Pöder et al., 2010). Of these symptoms, pain was the most problematic, distressing and prevalent symptom 1 week, 2 months, and 4 months postdiagnosis. Most recently findings from interviews with parents highlighted the need for them to manage pain in the context of a significant number of other new tasks following diagnosis (Flury et al., 2011).

## **Discussion**

The results of this review are considered and the implications for future research identified. Where appropriate,

research from outside the review will be drawn upon where it best illuminates the findings.

### *Sources and Prevalence of Cancer-Related Pain in Children*

Results indicate that children with cancer are now experiencing more pain from treatments and painful procedures than from the disease itself. Many studies report a high prevalence of pain in children with cancer however, no single figure for how many, or how frequently, children with cancer experience pain can be obtained. Younger children are regularly underrepresented in studies exploring children's cancer pain; on the whole they are rarely asked for their views. More research is needed to establish pain prevalence and characteristics particularly as all the studies investigating the sources of cancer pain were conducted prior to 2005. No studies, to date, can quantifiably report on levels of pain and how pain is managed outside the health care setting. The methodological flaws in literature examining pain management outside the health care setting make this an area where further research is required. In addition, the findings of the review revealed only one UK study on children's cancer pain (Collins et al., 2000). It is clear that further research is required to ascertain which findings can be applied to the United Kingdom.

### *Impact of Cancer-Related Pain on the Child and Other Family Members*

The impact of cancer pain on children, parents, and families is clearly significant, suggesting that improvements in pain management and resources to help manage pain effectively would be welcome. Parents feel unprepared to manage their child's pain along with many other new caring roles (Flury et al., 2011). Observing their child's cancer pain led parents to severe distress and pain themselves (Pöder et al., 2010).

There are surprisingly few resources on pain and pain management specifically available to parents. For instance, websites providing information for parents of children with cancer rarely provide information specifically relating to the assessment and treatment of pain at home. Given that parents often report pain as being one of the most difficult and distressing aspects of caring for a child with cancer, the paucity of resources available to inform and guide them in managing pain effectively needs to be addressed. Web-based resources have been used successfully in children with functional abdominal pain (Sato, Clifford, Silverman, & Davies, 2009) and arthritis pain (Stinson et al., 2012). Similar strategies such as the web-based resource for parents of children who have had day surgery ([www.mychild-ispain.org.uk](http://www.mychild-ispain.org.uk)) could be used to support parents to manage their child's cancer-related pain.

### **Parental Attitudes to Pain and Analgesic Drugs**

There are conflicting results about the fears parents may have about pain medication, in relation to potential side effects and addiction. Findings that parents report both restricting and encouraging pain medication (Rhiner et al., 1994), and that the use of analgesic drugs can be limited by parents at home (Forgeron et al., 2005; Van Cleve et al., 2004), suggests the need for further exploration. This apparent contradiction may in part be due to differences in study design, sample characteristics, and cultural differences in the countries where studies have been conducted. There is a need to further explore potential parental attitudinal barriers in the management of children's cancer-related pain.

These barriers have been documented relatively consistently in relation to parents' management of postoperative pain at home and in one US study relating to childhood cancer patients (Fortier et al., 2011). Research on the factors associated with parents' undermanagement of postoperative pain has generally focused on parents' attitudes about pain medication. Previous research has found that parents fear the side effects of analgesic drugs (Kankkunen, Vehvilainen-Julkunen, Pietila, Kokki, & Halonen, 2003; Sutters et al., 2012; Twycross, Williams, Bolland, & Sunderland, 2014; Zisk-Rony, Fortier, MacLaren-Chorney, Perret, & Kain, 2010), think they are addictive (Kankkunen, Vehvilainen-Julkunen, Pietila, Kokki, & Halone, 2003; Twycross et al., 2014; Zisk-Rony et al., 2010), and that children should receive as little pain medication as possible (Paquette et al., 2013; Twycross et al., 2014; Zisk-Rony et al., 2010). Indeed, many parents believe analgesic drugs work best when given less often (Helgadottir & Wilson, 2004; Kankkunen, Vehvilainen-Julkunen, Pietila, Kokki, & Halone, 2003; Zisk-Rony et al., 2010). Addressing uncertainties around the safety and efficacy of analgesic drugs, and the expression of pain in children, may be important areas for intervention, given their potential implications for the ways in which parents assess and treat pain at home. Fortier et al. (2012) note a trend toward more parents of children with cancer expressing strong agreement with misconceptions about pain medication, than in the surgical population. Overall, the available literature lacks conclusive findings and there is a need to explore this area further.

### **Parental Management of Their Child's Cancer-Related Pain**

At the time of this review no studies had investigated parents' actual pain management practices in this context. Findings relating to the attitudes of parents of children being treated for cancer are congruent with the research on parental attitudes toward pain and pain medication in

the postoperative period. Most parents consider that postoperative pain management in children is their responsibility, but many report finding this challenging (Kankkunen, Vehvilainen-Julkunen, Pietila, & Halonen, 2003). Parents can generally assess their child's pain, but this assessment does not necessarily lead to adequate analgesic dosing (Fortier, MacLaren, Martin, Perrett-Karimi, & Kain, 2009; Kankkunen et al., 2009; Unsworth, Franck, & Choonara, 2007). For example, parents often give less than prescribed doses of analgesics or use less potent analgesics than recommended (Fortier et al., 2009; Kankkunen et al., 2009; Huth & Broome, 2007; Paquette et al., 2013; Sutters et al., 2012; Wiggins & Foster, 2007; Wilson & Helgadottir, 2006; Zisk-Rony et al., 2010). Fortier, Wahi, Bruce, Maurer, and Stevenson (2014) have subsequently published the findings of an investigation into parents' actual pain management practices. They found the main reason given by parents for not administering analgesics was that the child was not in pain. In addition, parents who did not give analgesia held misconceptions about pain management and attitudes regarding the avoidance of analgesia (Fortier et al., 2014).

None of the studies included in this review tested interventions to support parents in managing their child's cancer-related pain. Several studies have explored this in the postoperative period. Teaching parents to use a pain assessment instrument has been explored as a way of improving how parents manage their child's pain (Kankkunen et al., 2009; Unsworth et al., 2007). However, in both these studies the use of a pain assessment instrument had no statistically significant impact on the doses of analgesic drugs administered. The effect of providing parents with an educational booklet about pain management has been tested in a number of studies (Huth, Broome, Mussatto, & Morgan, 2003; Le May et al., 2010). There was some evidence that parents' knowledge increased but resulted in little improvement in pain care. This indicates a need to explore the strategies used by parents to assess their children's pain, as well as a need to ensure that parents are adequately prepared for this role.

Three studies explored the impact of instructing parents to administer analgesic drugs around the clock (ATC) postoperatively. Wiggins (2009) asked parents to use an alarm clock to remind them to provide ATC doses of analgesics following tonsillectomy and adenoidectomy. They found that parents in the intervention group administered more doses of analgesic drugs on the second postoperative day, than parents not receiving this instruction. Two randomized controlled trials provided parents with instruction in ATC dosing of analgesics following a tonsillectomy (Sutters et al., 2004; Sutters et al., 2010). Children in the ATC dosing groups received significantly greater amounts of analgesics. In addition, in the 2010 study children receiving ATC medication had significantly lower pain intensity

scores (Sutters et al., 2010). These interventions provide some insight into how parental behavior might be changed in relation to the administration of analgesic drugs after surgery, but further testing is needed in the cancer population.

### Limitations of the Review

As this is a rapid review some articles may have been missed during the literature searching process. If a systematic review had been undertaken more databases would have been searched and could potentially have found additional studies. Furthermore, due to the heterogeneity of the literature, no data synthesis techniques have been used. Doing so could have added depth to the conclusions. A further limitation is that due to the wide scope of the review and the need to focus on the management of children's cancer pain by parents at home, sources and prevalence of children's cancer pain may not have been given the necessary attention. Finally, the weighting of citations given to each study may not have matched its contribution to the literature due to the wide range in quality of the studies discussed. However, this is the first review of the literature in the nursing and biomedical literature and as such provides insight into the state of current knowledge as well as areas for future research.

### Implications for Nursing Practice

Several implications for nursing practice can be drawn from this review. First, nurses must acknowledge that pain from procedures is a major source of pain in children with cancer. Nurses need to use appropriate pain management techniques (analgesic drugs and nonpharmacological methods) when conducting painful procedures as advocated in current best practice guidelines (Association of Paediatric Anaesthetists, 2012). Second, there is a need for parental education relating to managing cancer-related pain at home. Nurses need to ensure that parents understand how to assess their child's pain and how and when to administer any pain medications they have been given as well as stressing the importance of adhering to prescribed doses. Finally, it is important that nurses provide parents with appropriate safety-net advice (Roland, Jones, Neill, Thompson, & Lakhampaul, 2014). This includes guidance to parents on which signs and symptoms should influence their decision making and guide them when to seek help. For example, this should include information on signs of unmanaged pain as well as what to do and where to go if pain continues.

### Summary

This review has, for the first time, studied the research about the source and prevalence of cancer-related pain in

children as well as children and parents' experiences of this pain. Children continue to experience cancer-related pain which relates largely to the side effects of treatment and procedure-related pain throughout the disease trajectory. Little is known about the prevalence of pain outside the health care setting and more specifically at home. Children and parents find pain one of the more distressing aspects of the disease. Pain is described as having a huge impact on the whole family. Despite its impact, there is very little evidence about how parents manage this pain at home. There is some evidence to suggest that parents may hold misconceptions and attitudes which are barriers to effective pain management for children with cancer. This is of concern, given that children are spending less time in hospital and hence parents are managing cancer-related pain at home. Further research is needed to explore how parents manage their child's cancer-related pain at home as well as their experiences of doing so. Children's voices also need to be heard. This will allow resources to be developed to support parents in this context.

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