

Cancer-Related Pain and Pain Management: Sources, Prevalence and the Experiences Of Children And Parents

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Objectives of the Presentation

- To provide an overview of the rapid review process.
- To provide an understanding of the main themes in current literature on how parents manage their child's cancer-related pain at home.
- To provide recommendations for future research directions.

Background

- Children with cancer are increasingly cared for by parents at home rather than hospital (Flury et al., 2011)
- Children with cancer describe pain as problematic (Jacob et al., 2008)
- Little information about:
 - Parents knowledge
 - Parental attitudes
 - Experiences of outside the healthcare setting

Aims

To:

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

Methodology

What is a Rapid Review?

- To summarise
- To synthesise
- Within a given timeframe
- To identify research priorities

(Armitage and Keeble-Ramsay, 2009; Smith et al., 2013)

Methodology

Data Sources

- EMBASE
- CINAHL
- PsychInfo
- PubMed

- Hand searching

Search Terms

- child
- OR
- children
- OR
- pediatric
- OR
- paediatric
- AND
- cancer pain

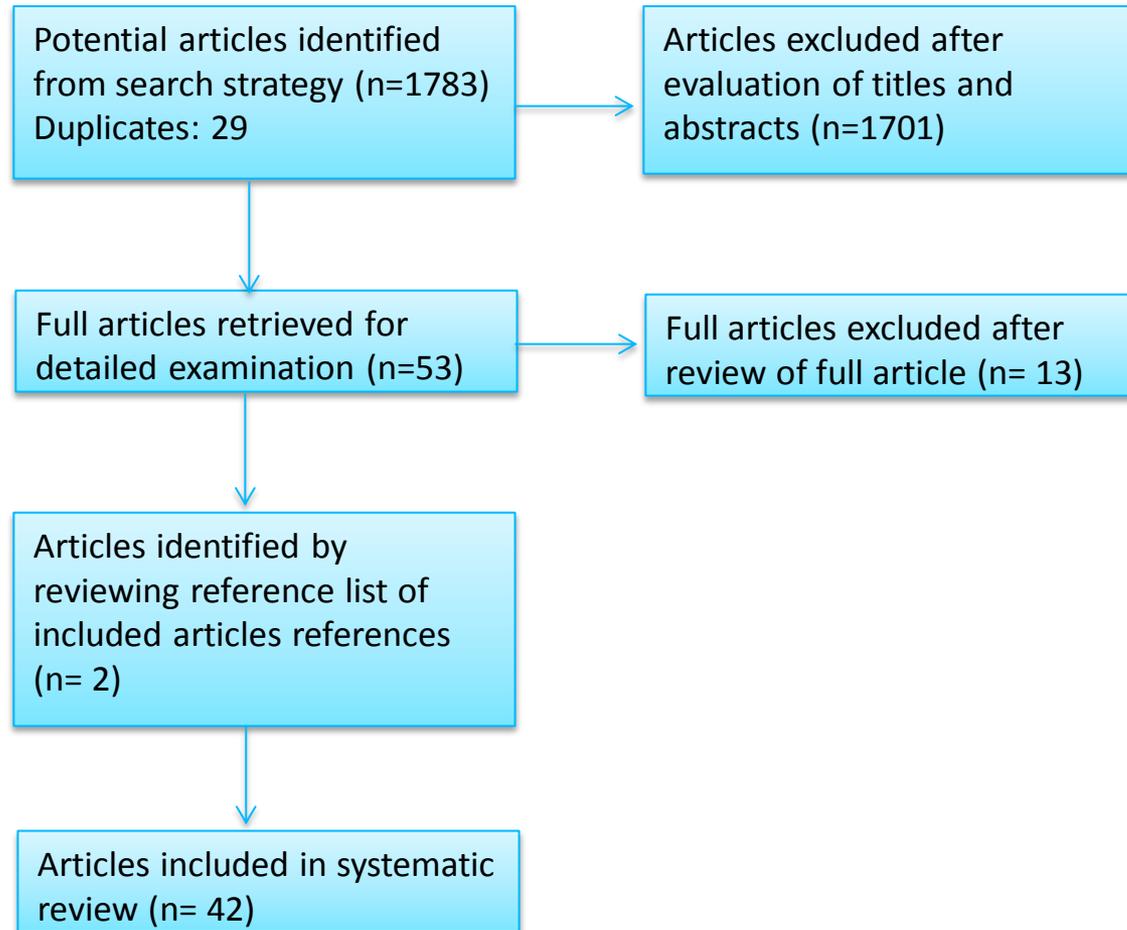
Methodology

Inclusion Criteria

- Peer-reviewed primary research exploring pain in children with cancer.
- Quantitative, qualitative, or mixed methods studies.
- Published in English between 1990 and October 2013.

Exclusion Criteria

- Palliative phase.
- Effectiveness of analgesic medications.
- Organisational structure of pain management services.
- HCPs perspectives only.
- Books, book chapters, commentaries & dissertations.



Flow diagram for retrieved, excluded and included studies.

Methodology

Quality Assessment

- Conducted by all 4 authors
- Caldwell et al. (2011)
- Critiquing tool rather than scoring
- Strengths and weaknesses of each study identified

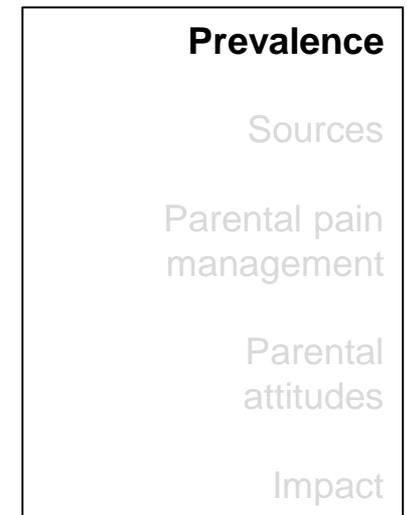
Results

- 42 papers
- Quality
- Themes:
 - Prevalence of pain: 8 studies
 - Sources of pain: 31 studies
 - Parental pain management: 15 studies
 - Parental attitudes: 7 studies
 - Impact of pain on the family: 6 studies

Prevalence

Results

- **One of, if not the most commonly reported symptom** (Collins et al. 2000, Hedstrom et al. 2003, Van Cleve et al. 2004, Williams et al. 2006, Miller et al. 2011)
- **Disease trajectory** (Bossert et al. 1996, Calissendorff-Selder & Ljungman 2006, Gedaly-Duff et al. 2006, Enskär and von Essen 2007, Walker et al. 2010)
- **Non-western cultures** (Forgeron et al. 2005; Yeh et al., 2008; Jacob et al., 2008)
- **Gender** (Hechler et al., 2009)
- **Age** (Friedrichsdorf et al., 2007; Van Cleve et al., 2012)
- **Symptom clusters** (Yeh et al., 2008; Baggott et al., 2012)



Prevalence

Discussion

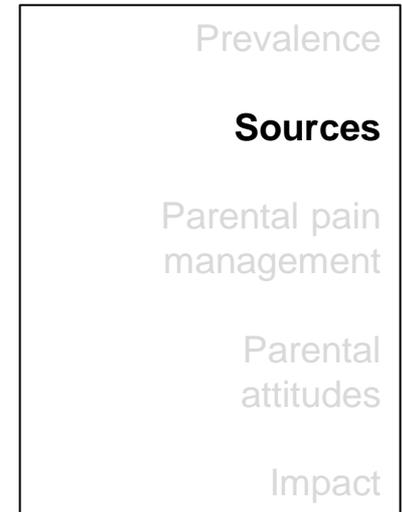
- No single prevalence figure can be obtained.
- Younger children are under-represented in studies (Collins et al., 2002; von Baeyer et al., 2013).
- No studies looking at prevalence outside the healthcare setting.



Sources

Results

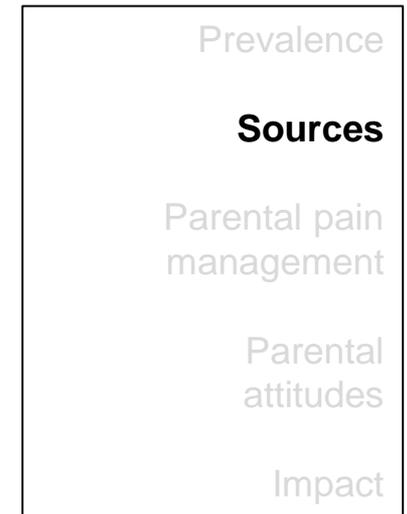
- **More pain from treatment and procedures** (McGrath, 1990; Blount et al., 2006; Ljungman et al., 1999; Fowler-Kerry, 1990)
- **Procedural-pain management** (Fowler-Kerry, 1990; Spagrud et al., 2008)
- **Procedural-pain measurement** (Walco et al., 2005)



Sources

Discussion

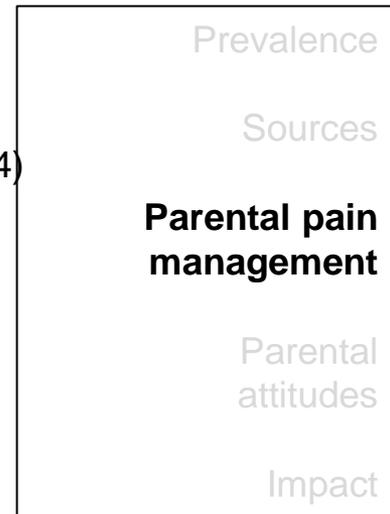
- More up to date studies on source needed.
- Methodological flaws in literature examining pain sources outside the healthcare setting.
- No studies have evaluated the effectiveness of interventions in children's cancer pain caused by procedures.



Parental pain management outside the healthcare setting

Results

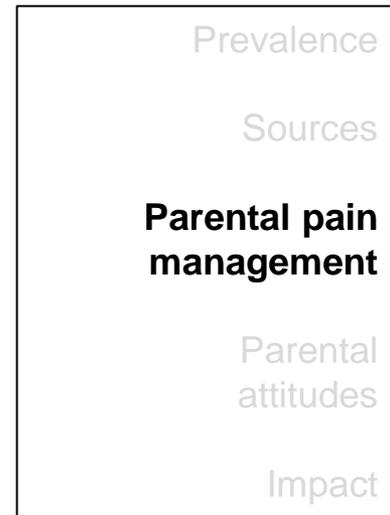
- Strategies to relieve pain – analgesic drugs, non-pharmacological (Van Cleve et al., 2004)
- Restrict medications, encourage medications (Rhiner et al., 1994)
- Frustrations (Rhiner et al., 1994)
- Need for education (Rhiner et al., 1994; Forgeron et al., 2005)



Parental pain management outside the healthcare setting

Discussion

- No methodologically sound studies outside the healthcare setting.
- No studies testing interventions to support parents.
- Similar findings to studies exploring parental management of postoperative pain.



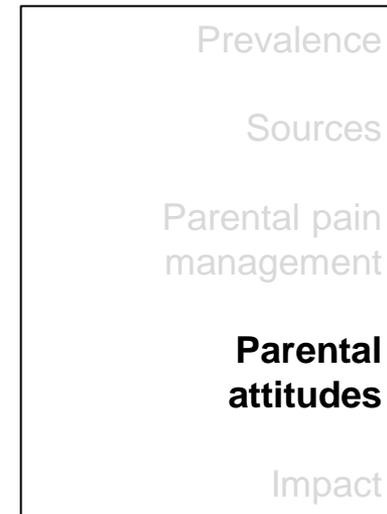
Parental attitudes

Positive

- **Analgesic drugs** (Lu et al., 2011)
- **Opioids** (Ljungman et al., 2006; Lu et al., 2011; Forgeron et al., 2005)
- **Parent and child pain ratings** (Badr Zahr et al., 2006)

Negative

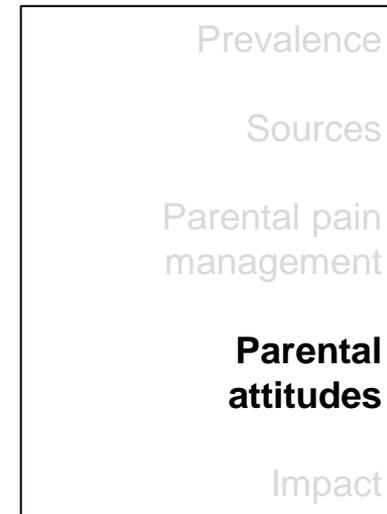
- **Concerns over side effects / addictions** (Ferrell et al., 1994a; Fortier et al., 2012)
- **Children exaggerate** (Fortier et al., 2012)
- **Children use pain to seek attention** (Fortier et al., 2012)



Parental attitudes

Discussion

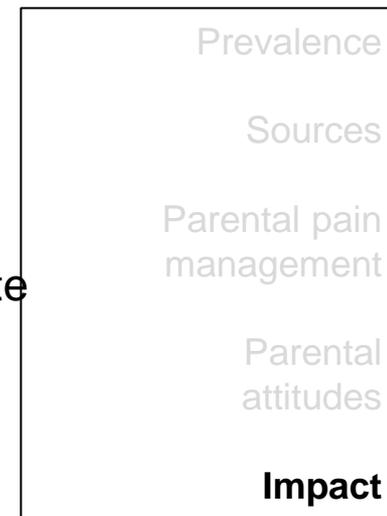
- Conflicting results
- Methodological differences
- Similar findings to studies exploring parental management of postoperative pain (Kankkunen et al., 2003b; Zisk-Rony et al., 2010; Sutters et al., 2012; Twycross et al., 2013; Paquette et al., 2013; Helgadottir and Wilson, 2004)



Impact

Results

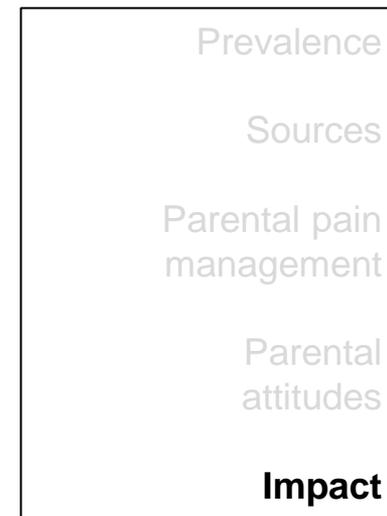
- Pain not taken seriously by HCPs (Ferrell et al., 1994a)
- Left parents feeling frustrated, helpless (Ferrell et al., 1994a)
- Pain was distressing and an emotional burden (Ferrell et al., 1994b; Forgeron et al., 2005; Post-White et al., 2009; Poder et al., 2010)
- Parents felt unprepared to manage pain (Ferrell et al., 1994b)
- One of many other tasks (Flury et al., 2011)



Impact

Discussion

- Scarcity of resources on pain management for parents
- Need to develop web-based resources?
- Other resources?



Limitations

- Papers missed during the literature search
- No data synthesis techniques
- Weighting of studies

Recommendations

More research to:

- Establish pain prevalence and characteristics.
- Clarify symptom clusters.
- Quantify levels of pain and how pain is managed outside the healthcare setting.
- Clarify parental attitudes.
- Develop pain management resources/interventions for parents.

Questions?