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
- children
- pediatric
- paediatric
- 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.

Potential articles identified from search strategy (n=1783) Duplicates: 29

Full articles retrieved for detailed examination (n=53)

Articles identified by reviewing reference list of included articles references (n= 2)

Articles included in systematic review (n= 42)

Articles excluded after evaluation of titles and abstracts (n=1701)

Full articles excluded after review of full article (n= 13)
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)


• 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.
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?