Attitudes towards pain expression and pain management in parents of children with cancer

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Outline

Background

Aim

Methods

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Discussion

Take home message
Background

Children experience pain throughout their cancer journey
   (Olsen & Amari, 2015; Twycross et al. 2015)

Pain has negative consequences
   (Berger et al., 2007; Huth et al., 2003)

Pain is treatable
   (Fortier et al., 2011)

Care location is changing
   (Fortier et al., 2014)

Parental pain management?
   (Flury et al., 2011; Twycross et al., 2015)
Aim

To explore attitudes of parents of children with cancer towards children’s pain and analgesic medications
SURVEY
Knowledge and attitudes

PAIN DIARY
Baseline measurements

INTERVIEW
Understanding

The ROYAL MARSDEN
NHS Foundation Trust

London South Bank University
Methods

Parental Pain Expression Perceptions questionnaire (PPEP)
- Zisk-Rony et al., 2007
- Pain assessment attitudes in parents
- Likert-type scale:
  - Strongly agree → strongly disagree
- 3 subscales

Medication Attitudes Questionnaire (MAQ)
- Forward et al., 1996
- Attitudes toward paracetamol and opioid administration
- Likert-type scale:
  - Strongly agree → strongly disagree
- 3 subscales

Demographic information
Inclusion criteria

• Parents of children with cancer
  • Parent:
    – Mother, father, guardian, any individual with primary caregiving responsibility
    – 18 years old and over
    – Sufficient English language and literacy to completed survey
  • Child:
    – Aged from birth – 16 years old
    – Any cancer diagnosis
    – On curative treatment
• Recruited from a tertiary cancer centre within the UK
• Target sample size: 100
Analysis

• SPSS
• Attrition
  – Chi squared
• Demographics and descriptive statistics
  – Tables, graphs, frequencies and percentages
• Inferential statistics
  – Time since diagnosis, Diagnosis, Parent ethnicity – Kruskall-Wallis
  – Gender – Student’s t-test
  – Child age – Pearson’s correlation
  – Parent age – Spearman’s rho

Analysis based on type of data and analysis of normal distribution
Statistical significance at p≤.05
Sample

- 101/161 (63%) participants who were approached returned a survey.
- 75 mothers, 20 fathers*
- 27 pre-school, 42 primary, 24 secondary*
- 60 boys, 36 girls*

*Chi-squared analysis comparing demographics of participation vs non-participation revealed no statistical significant differences
Child demographics – age

N=93

The graph shows the frequency distribution of child ages in years, with a peak at age 5 and a range from 1 to 16 years. The total sample size is 93.
Child demographics - diagnosis

N=95

- Leukaemia
- Solid tumours
- Brain
- Lymphoma
- Other
Parent demographics – age

N=98

The bar chart shows the distribution of parent age categories with the highest frequency in the 35-44 age group.
Parent demographics – education

N=95
Parent demographics – income

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than £14,000 per year</td>
<td>10</td>
</tr>
<tr>
<td>£15,000 - £24,000 per year</td>
<td>20</td>
</tr>
<tr>
<td>£25,000 - £39,000 per year</td>
<td>25</td>
</tr>
<tr>
<td>£40,000 - £59,000 per year</td>
<td>15</td>
</tr>
<tr>
<td>More than £60,000 per year</td>
<td>30</td>
</tr>
</tbody>
</table>

N=89
# Results – PPEP

<table>
<thead>
<tr>
<th>Statement on Parental Pain Expression Perceptions questionnaire</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children always express pain by crying or whining</td>
<td>48</td>
<td>1</td>
<td>51</td>
</tr>
<tr>
<td>Children always tell their parents when they are in pain</td>
<td>47</td>
<td>4</td>
<td>49</td>
</tr>
<tr>
<td>Children who are quiet are not in pain</td>
<td>62</td>
<td>3</td>
<td>34</td>
</tr>
<tr>
<td>Children who are playing are not in pain</td>
<td>59</td>
<td>1</td>
<td>40</td>
</tr>
<tr>
<td>Children experiencing pain report it immediately</td>
<td>56</td>
<td>5</td>
<td>40</td>
</tr>
<tr>
<td>Children exaggerate pain</td>
<td>46</td>
<td>15</td>
<td>39</td>
</tr>
<tr>
<td>Children complain about pain to get attention</td>
<td>52</td>
<td>6</td>
<td>42</td>
</tr>
<tr>
<td>Children feel less pain than adults</td>
<td>64</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>Children in pain have trouble sleeping</td>
<td>10</td>
<td>4</td>
<td>86</td>
</tr>
</tbody>
</table>
## Results – MAQ

<table>
<thead>
<tr>
<th>Statement on Medication Attitudes Questionnaire</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children should be given pain medication as little as possible because of side effects</td>
<td>37</td>
<td>24</td>
<td>38</td>
</tr>
<tr>
<td>Children who take pain medication for pain may learn to take drugs to solve other problems</td>
<td>43</td>
<td>23</td>
<td>34</td>
</tr>
<tr>
<td>Pain medication works the same no matter how often it is used</td>
<td>42</td>
<td>24</td>
<td>34</td>
</tr>
<tr>
<td>Pain medication works best when it is given as little as possible</td>
<td>40</td>
<td>22</td>
<td>38</td>
</tr>
<tr>
<td>Pain medication has many side effects</td>
<td>21</td>
<td>27</td>
<td>52</td>
</tr>
<tr>
<td>Children will become addicted to pain medication if they take it for pain</td>
<td>46</td>
<td>21</td>
<td>33</td>
</tr>
<tr>
<td>There is little need to worry about side-effects from pain medication **</td>
<td>49</td>
<td>18</td>
<td>33</td>
</tr>
<tr>
<td>It is unlikely a child will become addicted to pain medication if taken for pain **</td>
<td>17</td>
<td>33</td>
<td>50</td>
</tr>
<tr>
<td>Pain medication is addictive</td>
<td>29</td>
<td>28</td>
<td>42</td>
</tr>
<tr>
<td>Pain medication works best if saved for when the pain is quite bad</td>
<td>43</td>
<td>9</td>
<td>48</td>
</tr>
<tr>
<td>Using pain medication for children’s pain leads to later drug abuse</td>
<td>55</td>
<td>17</td>
<td>28</td>
</tr>
<tr>
<td>There is little risk of addiction when pain medication is given for pain **</td>
<td>21</td>
<td>18</td>
<td>60</td>
</tr>
<tr>
<td>Children learn how to use pain medication responsibly when it is given for pain **</td>
<td>10</td>
<td>27</td>
<td>63</td>
</tr>
<tr>
<td>Side effects are something to worry about when giving children pain medication</td>
<td>16</td>
<td>11</td>
<td>73</td>
</tr>
<tr>
<td>The less often children take pain medication for pain, the better the medicine works</td>
<td>37</td>
<td>25</td>
<td>37</td>
</tr>
<tr>
<td>Giving children pain medication for pain teaches proper use of drugs **</td>
<td>21</td>
<td>33</td>
<td>46</td>
</tr>
</tbody>
</table>

** Indicates reverse scored items
Results

Child factors
• Gender
• Age
• Diagnosis
• Time since diagnosis

→ No statistically significant differences

Parental factors
• Ethnicity.
  • A difference was found between Asian parents and white parents
  • A difference was found between Asian parents and parents of ‘other’ ethnicity
• Age
  • Spearman’s rho revealed lower MAQ scores with higher age
Comparison to other populations

More negative attitudes and misconceptions than other studies using PPEP and MAQ

**Example**

55% disagree “Using pain medication for children’s pain leads to later drug abuse”

- Zisk *et al.*, 2007 (Surgery, US): 80% disagree
- Zisk *et al.*, 2010 (Outpatient surgery, US): 86% disagree
- Fortier *et al.*, 2012 (Cancer, US): 70% disagree
- Twycross *et al.*, 2014 (General, UK): 84% disagree
Summary

• Parents of children with cancer hold negative attitudes and misconceptions
  – No improvements with time since diagnosis
  – Fewer with age
  – More in Asian populations

• More negative attitudes and misconceptions than other populations
Take home message

Awareness that more must be done to challenge negative attitudes and misconceptions of parents of children with cancer so that they do improve with exposure to healthcare settings.
References


Thank you
- Supervisors: Alison Twycross, Theresa Wiseman, Stephen McKeever
- Staff, patients and families at The Royal Marsden

Any questions?

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