Lay Summary for completed research projects

<table>
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<tr>
<th>CCR No and Study Title:</th>
<th>4569: An exploration of how parents manage their child’s cancer-related pain at home</th>
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| CI and Sponsor names:  | CI: Theresa Wiseman  
Sponsor: The Royal Marsden NHS Trust |
| Study opening date:    | 05/12/16  
Study closing date:    | 09/05/18 |

**Proposal and Objectives:**
There is a trend towards children with cancer spending more of their cancer journey at home and less time in hospital. Whilst this improves quality of life, it incurs a shift in responsibility for pain management from nurses to parents. This pain management role is one which parents have reported to find challenging. There is a lack of knowledge relating to how parents manage children’s cancer-related pain at home. This study aims to understand the experiences and behaviours of parents of children with cancer as their responsibility for managing their child’s pain increases.

**Main Findings:**
Survey results revealed parents of children with cancer hold negative attitudes and misconceptions which do not change with exposure to healthcare settings.

Pain diary results revealed frequent under medication of clinically significant pain accompanied with a preference for non-analgesic drug interventions.

Interview results were incorporated into a model of pain management with the key theme of ‘every child is different’. Themes of situational factors and a parental response were clustered around four phases of pain management: context, learning, intervention, and consequence.

Pharmacological factors mean parents are often unable to administer paracetamol, ibuprofen and morphine. Children find medications non-palatable and frequently refuse medications even when they are available.

Evidence suggests children with cancer experience pain in a variety of locations, primarily caused by treatment side-effects and have heterogeneous pain trajectories.

Divergent evidence that parents do and do not learn to assess children’s pain at home have several potential explanations.

Parents have a strong preference for non-analgesic medication interventions due to attitudinal and practical barriers to analgesic medication administration which result in parents having an ‘empty toolkit’. Non-analgesic medication interventions are essential to parents managing their child’s cancer pain at home.

**Implications for practice/future research:**
Children with cancer continue to experience clinically significant pain at home. Parents hold misconceptions and negative attitudes towards children’s pain and pain medication which healthcare professionals need to be aware of when discharging children.
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<th>Healthcare professionals need to be aware of the pressures and challenges parents face when managing their child’s pain at home. Parents need to ensure parents are educated as to when it is safe to administer analgesic medications and promote the use of non-analgesic drug interventions. Parents in this research alluded to interventions which may assist them, but this was not the focus of the research. Further research is required to ascertain types of interventions which parents will find most valuable.</th>
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<td><strong>Dissemination Plan:</strong></td>
<td>Results will be disseminated via peer reviewed journals and conference presentations. Conferences include the RCN International Nursing Research Conference in Birmingham and Pain in Child Health in Copenhagen. Participants who have requested it, will receive a copy of the results.</td>
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